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JULY 2021
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PLUS:

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AND • A CHAMPION FOR CHANGE:

CELEBRATING EUNICE SHRIVER'S LEGACY

CONTENTS

JULY 2021 VOLUME 51 ISSUE 7

ACCESSIBLE HOMES

COVER STORY

EP LOOKS BACK: JULY 2012

Building a Barrier Free Home
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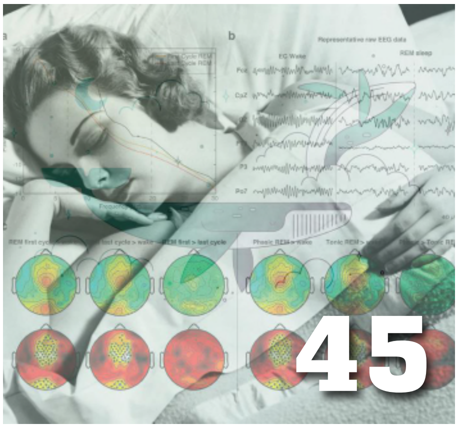
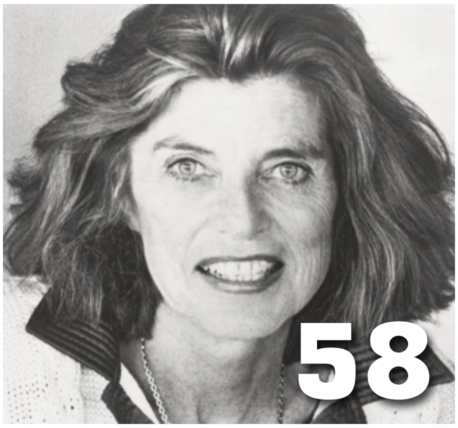


FEATURES

50 FOR 50 • PART II

PART II OF II

EP MAGAZINE SLEEP SERIES



ON OUR COVER

By reducing the challenges in a person's environment, it becomes easier to accomplish activities of daily living. EP addresses adaptability and affordability in its Annual Accessible Homes Issue. *Coverage begins on page 13.*

CONTENTS

JULY 2021 VOLUME 51 ISSUE 7

DEPARTMENTS

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Information and Support for the Special Needs Community

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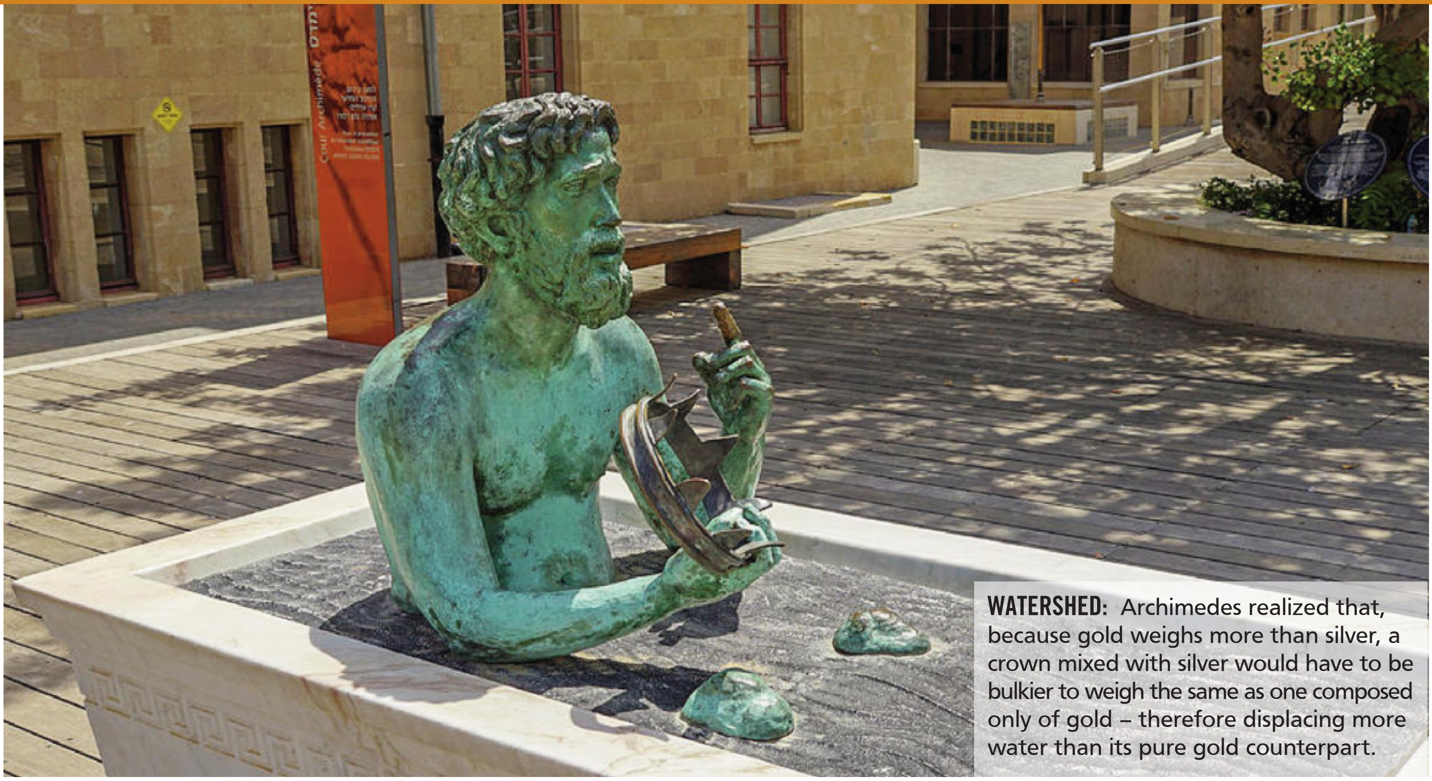
Note from the Editor-in-chief: EP World, Inc. advocates for the dignity of all citizens with disabilities including the use of "people first language" where possible. We do not normally edit articles and submissions that do not reflect this language, therefore, at times, readers might see alternative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



WATERSHED: Archimedes realized that, because gold weighs more than silver, a crown mixed with silver would have to be bulkier to weigh the same as one composed only of gold – therefore displacing more water than its pure gold counterpart.

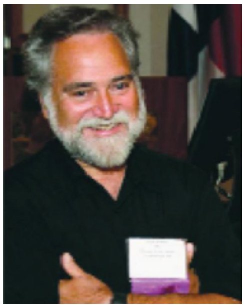
I Have Found It!

Most of the time, our "Eureka" or "Aha!" moments don't come when we are diligently searching for them.

I had one the other day and not while I was taking a bath. I was in my garage, trying to get an old car started that was undisturbed for twenty years. I did what good mechanics do, and that was to replace all the old parts that were responsible for it to hiccup and come to life. No hiccup, no dice, no belching and no ignition. I went through the procedure over and over again and nothing made sense. The parts were all new, so where did that leave me? Perhaps I was assuming too much. What if I was negating the logical illogical and what was a new part could have been a bad part? I had my Eureka moment. One of the new parts had to be defective, even though they were new and out of the box. Sure enough, one of the new gizmos was defective and its replacement woke the sleeping beast.

I indicated that the moment came to me and I was not taking a bath. I said that, not because I typically have insights in the bathtub; in fact, I prefer showers. But the statement is a tribute to history's first recorded Eureka moment.

Archimedes was among the greatest scientists of all time. He was a gifted physicist, mathematician, astronomer, inventor and engineer. The king of Syracuse (island off of Sicily) commanded a goldsmith to make a suitable crown for him (the King) to wear. While it was of a magnificent design, the King thought that the color of the crown was suspicious and wanted Archimedes to check to see if it was pure gold as ordered.



Archimedes was perplexed by the challenge. The crown weighed as much as the gold that was given to the craftsman. One day, Archimedes was about to take a bath and he did not notice that the water was already full to the brim. When he slid into the bathtub, a large quantity of water flowed over the top of the bathtub. It hit him. He jumped out of the bathtub shouting, "Eureka! Eureka!" For those of you who can only read the Greek letters over the door of a college fraternity house, "eureka" is Greek for "I have found it."

What he "found" was that different metals of the same weight have different volumes. Objects, put in water, will displace water. The displaced water will be equal to their volume. The craftsman used inferior metals that were equal to the weight of the gold. So, before you relegate what is now known as the Eureka moment to a distant bathtub, know that the Archimedes principle has served as the basis for studies in bone density, aging studies and medical-related studies involving fluid dynamics.

One can imagine Archimedes sitting in his bathtub, watching the water spill onto the floor and thinking, "That's funny."

But that line is credited to another amazing scientist and leading science fiction writer, Isaac Asimov, “The most exciting phrase to hear in science, the one that heralds new discoveries, is not ‘Eureka” but ‘That’s funny.”

Most of the time, our “Eureka” or “Aha!” moments don’t come when we are diligently searching for them. While it happened in the bathtub for Archimedes, Newton experienced it while wandering an apple orchard. Arthur Fry, (the inventor of Post-it notes) had it while pulling paper off a wall that failed to stick as he had hoped. For George de Mestral, a Swiss engineer, it happened from a walk in the woods with his dog in 1941. Upon their return home, de Mestral noticed that burrs had attached themselves to his pants and to his dog’s fur. He carefully examined the burrs and it led to the discovery of Velcro. Burrs have attached themselves to pants and fur for centuries but for one person, it was an “Aha!” moment.

> “The disability movement has had many ‘Aha!’ moments, most recently ‘Nothing about us without us.’”

In a recent article in the journal, Brain World, they shared that “There are many words and terms that we use to describe good ideas – “sparks, flashes, light-bulb moments; inspirations and innovations; muses and visions. But what makes these moments so mystifying is that they usually materialize abruptly, without warning and seemingly out of thin air.”

For over a century, researchers have attempted to study the phenomenon of “Eureka” or “Aha!” moments. We now understand that we require more neural processes operating at different time scales to achieve a “flash point of understanding” than we use when solving a problem analytically or methodically. Using advanced functional magnetic resonance imaging and electroencephalographic sensors, we know that “gamma activity” (and I don’t want to lose you here) coming from the brain’s right hemisphere (where we begin to assemble parts of a problem and create associations) is working overtime. This activates a neural pathway that spikes new ideas.

The term “Aha!” moment came into prominence in 2012 when Merriam-Webster released their annual list of new dictionary words. Interestingly enough, “aha moment” made it above “bucket list”, “game changer”, and “sexting”.

And while she is not a neuroscientist, Oprah Winfrey has a very compelling and thought-provoking explanation of what exactly is an “aha moment.”

“The thing about an Aha! moment is that you think you’ve never thought of it that way before… But you can’t have an ‘aha’ unless you already knew it. So the aha is the remembering of what you already knew, articulated in a way to resonate with your own truth. So, the aha isn’t somebody teaching you something; the Aha! is somebody helping you to remember.”

Research from Reber (*Current Directions in Psychological Science*) assumes that there are four parts of an “Aha!” moment. First, the “Aha!” moment appears suddenly; second, the solution to a problem can be processed smoothly; third, the “Aha!” moment elicits positive affect; fourth a person experiencing the “Aha!” moment is convinced that a solution is true.

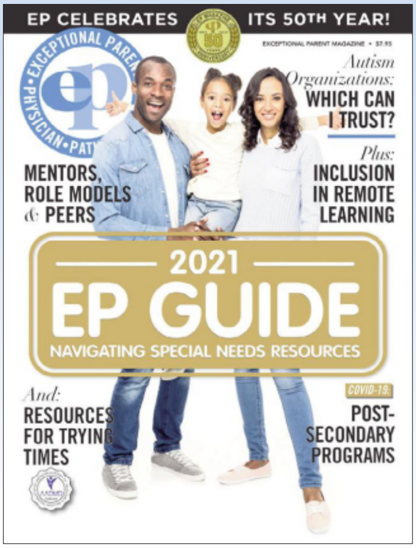
The disability movement has had many such moments. First, it was, “It doesn’t have to be like this.” Shortly after that was, “We have many voices.” That was followed by “Our stories must drive the message,” that was followed by, “We can do this,” and most recently, “Nothing about us without us.”

What amazes me is, how did they all fit into that bathtub? •

ANCORA IMPARO

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

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



WHAT'S HAPPENING

EP MAGAZINE APPOINTS DR. STEVE PERLMAN AS SENIOR EDITOR FOR SPECIAL PROJECTS

It's appropriate that EP Magazine has named Steve Perlman, DDS as the Senior Editor for Special Projects. Appropriate because the term "Special" is part of Dr. Perlman's DNA. Steve was the founder of the Healthy Athletes Program at Special Olympics.

Dr. Perlman has been instrumental in practicing, promoting and perfecting "special" care dentistry for five decades. He has mentored thousands of dental students by exposing them to the "special" rewards that comes with treating people with "special" healthcare needs. A longtime member of *EP Magazine*'s Editorial Advisory Board, Steve has played a vital part in helping the magazine to become the nation's most respected resource for the disability community.

THE DOCTOR IS IN: Dr. Perlman has dedicated his career helping those with ID receive access to health care.

In his new role as Senior Editor for Special Projects Dr. Perlman will be responsible for identifying evolving topics in healthcare, recruiting national experts, creating single subject monographs, creating webinars, and serving as our liaison to national healthcare, advocacy and support organizations. He is skilled in bringing together opinion leaders, communicating with global notables in intellectual and developmental disabilities, and is admired and respected by individuals with disabilities, academia, industry, families, clinicians and policy makers. While he has "retired" from active clinical practice, his seven-day-a-week schedule would have you thinking otherwise. Welcome Dr. Perlman. For *EP Magazine*, it's the ultimate 50th Anniversary gift to ourselves and our readers.

– Rick Rader, MD, Editor in Chief,
EP Magazine

BRIDGING HEALTH DISPARITIES : CATCHING UP WITH DR. STEVE PERLMAN

Dr. Steven Perlman is a Clinical Professor of Pediatric Dentistry at the Boston University Goldman School of Dental Medicine. For the over 45 years, he has devoted much of his private practice, as well as his teaching, to the treatment of children and adults with physical and intellectual disabilities. He is the founder of the Healthy Athlete program for Special Olympics and co-founder of the American Academy of Developmental Medicine and Dentistry. He is the recipient of many National and International Humanitarian and other awards related to his work in advocacy, policy and education.

A past president of the Academy of Dentistry for Persons with Disabilities, the Massachusetts Academy of Pediatric Dentistry, and the American Academy of Developmental Medicine and Dentistry (AADMD), Dr. Perlman is also a Fellow of the Academy of Dentistry for Persons with Disabilities, and the American College of Dentists, and a Diplomate of the American Board of Special Care Dentistry. He is co-founder and past president of the AADMD, and in 2005 and 2006, he served as an advisor to the President's Committee for Persons with Intellectual Disabilities.

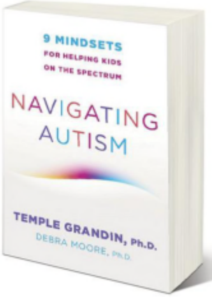
In 1993, Dr. Perlman founded Special Olympics Special Smiles, an oral health initiative for the athletes of Special Olympics International. It now has over 200 events each year, taking place in every state in the United States and in over 100 countries. He currently serves as their Senior Global Clinical Advisor. In 2008, in Shanghai, China, Special Olympics honored Dr. Perlman with a special Lifetime Global Leadership Award in promoting human dignity. He was the first dentist in Massachusetts to receive the Exceptional Physician Award. He is a Distinguished Alumnus of the Boston University Goldman School of Dental Medicine, and the first graduate in the history of the Dental School to also be recognized as a Distinguished Alumnus of Boston University.

THE WHOLE WORLD SMILES: Dr. Perlman created Special Olympics Special Smiles to provide free dental screenings for Special Olympics athletes. Today, this is one of eight disciplines offered by Special Olympics Healthy Athletes, a program that offers free health screenings to Special Olympics athletes worldwide.

WHAT'S HAPPENING

NEW BOOK ON NAVIGATING AUTISM FROM TEMPLE GRANDIN AND DEBRA MOORE

Norton Mental Health announces the September 21 publication of Temple Grandin and Debra Moore's "Navigating Autism: 9 Mindsets for Helping Kids on the Spectrum."



Title: **Navigating Autism: 9 Mindsets for Helping Kids on the Spectrum**

Author: **by Temple Grandin** with **Debra Moore**

Publisher: **W. W. Norton & Company**
Publication Date**: September 2021**
Paperback: **384 pages**
ISBN-13: **978-0393714845**
Available at: amazon.com and www.barnesandnoble.com

Dr. Grandin shares personal experiences and anecdotes from the thousands of parents and professionals who have sought her advice, while Dr. Moore draws on more than three decades of work as a psychologist with kids on the spectrum and those who love and care for them.

This book will help mental health clinicians, physical, occupational, and speech therapists, parents, and anyone interacting with children or teens in the spectrum broaden their outlook and come away with new, empowering mindsets they can apply to develop the full potential of every child.

Temple Grandin, PhD, is an internationally best-selling author, and Professor of Animal Science at Colorado State University. In 2020 she was honored as a Top Ten College Professor in America. In 2010, Time 100, an annual list of the 100 most influential people in the world, named her in the "Heroes" category.

Debra Moore, PhD, is a psychologist who has worked extensively with children, teens, and adults on the autism spectrum. She was the Founder and Director of Fall Creek Counseling Associates. She devotes her time to volunteering and writing. This is her second project with Dr. Grandin, coauthoring *The Loving Push: How Parents and Professionals Can Help Spectrum Kids Become Successful Adults* in 2016. •

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE & DENTISTRY

The Proportion of Children with Disabilities Varies Greatly in US States

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

NUMBERS AND PERCENT

The following findings for 2018-2019 are from the latest National Survey of Children's Health by the Data Resource Center for Child and Adolescent Health. It was estimated that **18.9%** of U.S. resident children and adolescents **(13,871,360 youngsters: 0 to 17 years of age**) had one or more disabilities. The percent of this population with disabilities by state ranged from 13.8% in Hawaii to 24.2% in Louisiana. *(see Table 1)* [1]

By gender, the percent of young females with disabilities was less than their male counterparts; ranging among **females** from 11.6% in Nevada to 22.3% in West Virginia. The percent of young **males** with disabilities ranged from 15.5% in Hawaii to 27.0% in New Hampshire. *(see Table 2)* [1]

By race and ethnicity, the percent of young Hispanics with disabilities ranged from 8.4% in Indiana to 39.2% in North Dakota.

The percent of young **White non-Hispanics** with disabilities ranged from 11.8% in the District of Columbia to 25.8% in Texas.

The percent of young **Black non-Hispanics** (for 31 states) ranged from 13.2% in Nevada to 41.0% in Oklahoma. *(see Table 3)* [1]

Nationally, among **adults** in 2020, 61 million (26%) lived with a disability.

- An estimated 12.7% percent of the **entire** U.S. population had a disability.
- The estimated **total state** resident population with one or more disabilities ranged from 9.1% in Vermont to 19.8% in West Virginia. *(see Table 4)* [2,3]

Table 1. *Five states with the lowest and highest percentage of youngsters with disabilities: 2018-19* [1]

Lowest Percentage		Highest Percentage	
Hawaii	13.8%	Oklahoma	22.9%
California	14.0	Maine	23.0
Nevada	15.5	N. Hampshire	23.7
Utah	16.2	W. Virginia	24.0
N. Jersey	17.0	Louisiana	24.2

PROVIDING FOR THE YOUNGSTERS AND NOT SO YOUNG WITH DISABILITIES

By economics: Medicaid represents $1 out of every $6 spent on healthcare in the US and is the major source of financing for states to provide coverage to meet the health and long-term care needs of their low-income residents. The federal share of Medicaid is determined by a formula set in statute that is **based on each state's per capita income.**

The formula is designed so that the federal government pays a larger share of program costs for the **poorer states.** The federal share varies by state from a low of 50% to a high of 77% in 2020. The poorer states, i.e. those states that contributed a smaller percent of Medicaid costs, their share ranged from 21.1% for New Mexico, to 21.3% for West Virginia, 22.0% for Kentucky, 22.4% for Montana and 23.2% for Arizona. [4,5]

The **Supplemental Security Income** (SSI) program is one of the few federal programs to provide monthly cash assistance to low-income families of children with intellectual disabilities that result

Table 2. *Five states with the lowest and highest percentage of female & male youngsters with disabilities: 2018-19* [1]

Lowest Percentage			
Females		Males	
Nevada	11.6%	Hawaii	15.5%
California	11.9	California	16.1
Hawaii	12.0	Nebraska	18.1
N. Dakota	3.3	Utah	18.2
N. Dakota	13.9	New Jersey	18.2
Highest Percentage			
Females		Males	
Kansas	20.8%	Connecticut	25.8%
Oregon	21.3	Oklahoma	25.9
Maine	21.5	Louisiana	26.8
Louisiana	21.9	Mississippi	26.8
W. Virginia	22.3	N. Hampshire	27.0

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY

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

in severe impairment. SSI eligibility often improves access to health services for children with intellectual disabilities as it assures referral to other state programs. There are **unexplained and large discrepancies across states** *(emphasis added)* in the review and receipt of SSI benefits for low-income children with mental disabilities. [6]

By educational programs: Inclusion of students with disabilities in the least restrictive educational environment has proven to be valuable in educating students with disabilities. Historically, beginning with the passage of PL 94-142 (1975), the inclusion of students with disabilities in the least restrictive environment has become a focal point for litigation and a rallying issue for advocates. Yet, it is not generally known that levels of inclusion vary wildly across states and school districts. "Recent data show variations by state from **34% to 91%** *(emphasis added)* in the proportion of special education students who are 'fully included' in general education settings." [7]

By jobs: In 2020, 17.9% of persons with a disability were employed, (down from 19.3 percent in 2019). For persons without a disability, 61.8% were employed in 2020, (down from 66.3% in the prior year). The unemployment rates for persons with and without a disability both increased from 2019 to 2020, to 12.6% and 7.9%, respectively. Data regarding both groups for 2020 reflect the impact of the coronavirus (COVID-19) pandemic. Nevertheless, a large proportion of persons with a disability (about 8 in 10) were not in the labor force in 2020, compared with about 3 in 10 of those with no disability. In part, this reflects the older age profile of persons with a disability.[8]

At the state level, the employment rate of individus with disabilities ranged from 26.1% in West Virginia to 56.3% in North Dakota. *(see Table 5)* [9]

Table 3. *Five states with the lowest and highest percentage of youngsters with disabilities by race and ethnicity: 2018-19* [1]

Hispanics		White-non-Hispanics		Black non-Hispanics*	
Lowest Percentage					
Indiana	8.4%	Dist. of Columbia	11.8%	Nevada	13.2%
Idaho	11.0	Hawaii	12.3	Texas	13.3
Iowa	11.3	North Dakota	14.9	California	14.9
California	11.6	Utah	15.2	Maryland	16.2
Florida	12.3	Virginia	16.3	New Jersey	17.1
Highest Percentage					
Connecticut	27.9%	Kentucky	22.8%	Pennsylvania	27.9%
Alabama	28.6	Maine	23.8	Missouri	28.9
N. Hampshire	28.6	West Virginia	24.2	Louisiana	29.0
W. Virginia	31.1	New Hampshire	24.4	Indiana	35.6
N. Dakota	39.2	Texas	25.5	Oklahoma	41.0

***19 states not included**

MAPS AND LEGENDS: When seeking to find the best cities to raise a child with special needs, a parent usually considers factors like the availability of housing, affordable family entertainment options, proximity to hospitals and, of course, being within the best school districts in the county.

Table 4. *Five states with the lowest and highest percentage of the total population with disabilities, 2019* [2]

Lowest Percentage		Highest Percentage	
Vermont	9.1%	Mississippi	16.8%
New Jersey	10.4	Maine	16.9
Colorado	10.6	Arkansas	17.5
California	10.6	Kentucky	17.8
Minnesota	10.8	W. Virginia	19.8

Table 5. *Five states with the lowest and highest percentage of employment rate of individuals with disabilities* [9]

Lowest Percentage		Highest Percentage	
West Virginia	26.1%	Minnesota	47.8%
Alabama	26.8	Nebraska	49.3
Mississippi	27.6	Utah	49.5
Kentucky	30.2	South Dakota	51.3
Arkansas	30.8	North Dakota	56.3

BEST PLACES TO LIVE IN THE US WITH CHILDREN WITH SPECIAL NEEDS

A study of the nation's 150 most populated cities across three primary dimensions that impact on the disability community (economic environment, quality of life and health care report) ranked them:

1. Overland Park, KS
2. Scottsdale, AZ
3. Peoria, AZ
4. Tampa, FL
5. St. Petersburg, FL

146. Worcester, MA
147. Moreno Valley CA
148. San Bernardino, CA
149. Jersey City, NJ
150. Providence, RI [10,11]

When seeking to find the best cities to raise a child with special needs, a parent usually considers factors like the availability of housing, affordable family entertainment options, proximity to hospitals and, of course, being within the best school districts in the county. However, for parents of children with special needs, there are often more important factors involved. Your child with special needs is unique and has extraordinary requirements. Only you and your support team can make these essential decisions.

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

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NAVIGATE YOUR HOME SAFELY AND EASILY WITH THESE SIMPLE MODIFICATIONS

BY LYNDA SHRAGER

After spending more than a dozen years in the home care arena providing occupational therapy services, my frustration level continued to rise as I was always brought in to treat my patients ***after*** *the crisis occurred. Whether it was a slip getting into the tub in the bathroom, a fall reaching for the light in the living room, or a loss of balance reaching for something in the kitchen, these often-serious injuries resulting in trips to the emergency room could have easily been avoided.*

As an occupational therapist, my treatment practices are guided by the Environmental Press theory, a theory suggesting that the more a person's environment presents challenges, the harder it is to function in that environment. By reducing the challenges, it becomes easier to accomplish activities of daily living, fundamental skills that are required to independently care for oneself. My focus shifted to helping my patients with physical and cognitive challenges make their homes more livable and safer *before* a crisis occurred.

This article highlights the process of conducting environmental home assessments, beginning with observing how the client navigates from the outside in and throughout their home. Those observations are the basis for creating a plan to address any problem areas to help them remain in their homes, aging comfortably and safely in place.

PHOTOS PROVIDED BY LYNDA SHRAGER

GET OUT THERE: Once the stairlift *(left)* was installed, the family was able to transfer their mother into the chair to "go for a ride" to the backyard; Another client needed a low, rounded rail *(right)* which was the optimal size and shape for her to grasp.

ENTRANCES AND EXITS

One of my most challenging scenarios was working with an elderly woman suffering with amyotrophic lateral sclerosis who lived with her daughter. The home was built on a sloping lot that required eight steps to access the front door. The family needed several helpers to get mom up and down the front stairs. Since it was often difficult to gather the troops, most of the time she was stuck in her house. The kitchen led out to a back deck that had a long staircase leading down to the backyard. Thinking "outside the house" I suggested that they install a stairlift on the back deck staircase. The family was unaware that this was even a possibility. Stairlifts are not inexpensive, costing between $2000 and $5000. They are covered by some state Medicaid waiver programs and help for financing may be found through foundations and disease-specific organizations. For this family, the benefit was priceless. Once installed, they were able to wheel her out through the kitchen onto the deck, where she could transfer into the chair and "go for a ride" down to the yard. To protect the stairlift in inclement weather, they covered it with a tarp. She was no longer a prisoner in her own home.

Assessments begin with observing the patient's ability to safely enter and exit the home, a simple function that can be surprisingly difficult. Entranceways to homes are as diverse as the homes themselves. The ideal scenario is to have a no-step entrance to the house, also referred to as a zero threshold. This can be accomplished by grading the walkway from the driveway and/or front sidewalk to lead up to the front door via a slow, gradual pitch. Front entrances without a zero threshold usually have some type of stairway leading to either a porch or a platform leading to the front door. I always recommend at least one handrail to assist going up and down the steps.

A client was moving into an old farmhouse and, due to a recent stroke, she could not raise her arm high enough nor open her hand wide enough to hold the rail. The solution was to add a lower, rounded railing which was the optimal size and shape for her ability to grasp it.

GENERAL LIVING AREAS

When thinking about safety and mobility throughout the living areas in a house, we often neglect to look closely at the furniture. Arthritic knees and hips and general weakness can wreak havoc on the ability to get on and off of a low, soft cushion. The higher the height of a chair or couch, and the firmer the cushion, the easier it is to get on and off.

Lights, walking surfaces, and windows should be evaluated for safety and convenience. Light switches should ideally be placed in an accessible location near the entrance to a room. Illuminated touch or rocker-type switches are the easiest to use for those with fine motor disabilities. Regular lamps can be eas-

HOLD ON: *(Left to right)* Door thresholds can ease transitions between rooms; Holding a grab bar made a woman feel safer and more confident accessing this sunken den; Hallway rails can provide much-needed support and security, at night.

ily converted to touch-sensitive lamps, which are activated by the touch of a hand rather than by a switch. Good lighting is a key safety feature of any home, and as we age, we need more light.

The ideal flooring is one that is flat with no changes in surface. For those whose disabilities may lead to impairment in vision and balance, changes in floor surfaces can negatively impact their ability to walk around the house. Door thresholds can be installed in between rooms to smooth out the gaps. If carpeting is preferred, one with a low pile of less than 1/2 inch is optimal. Wood, linoleum, and tile are easier for wheelchair users. These surfaces should be kept clean but not so highly polished that they become slippery. If opting for tile, select a type with texture for more traction.

SUNKEN ROOMS

Sunken rooms come in and out of architectural fashion. One recent assessment involved a friend whose mother-in-law needed to move in for a few months. The kitchen led into a sunken den where she would be spending a lot of time and her Parkinson's made it hazardous for her to get down the two steps. We analyzed where she would need to hold onto for the best mobility, and then added a grab bar under the countertop to provide support. Holding this rail made her feel safer and more confident accessing this room.

HALLWAYS

To increase safety, install a light at both ends of the hallway. Installing a railing in a hallway can provide much-needed support and security, especially for those late-night "runs" from the bedroom to the bathroom.

KITCHEN

The kitchen is often the heart of the home and the place where family and friends tend to congregate. Although a large renovation to alter the size and overall layout may be prohibitive, there are numerous ways to modify areas to make it easier to navigate. In general, an open floor plan makes it easier for two people to be in the kitchen together, and if one is on crutches or using a walker, the wider the open space, the more room to move around. If someone is in a wheelchair, a 5-foot diameter of open space is an ideal turning radius. If counters are not at an ideal height, the kitchen table can be used as a workstation, or a portable kitchen island can be added to the space. If possible, one workstation should be 27 inches off the floor and open underneath, making it accessible for someone who is seated. Consider lowering some cabinets and using D-shaped handles as they are the easiest to grasp for those with decreased strength and mobility in their hands.

A side-by-side refrigerator is the easiest for everyone to access, especially someone in a wheelchair.

Bump dots provide a tactile clue for the visually impaired.

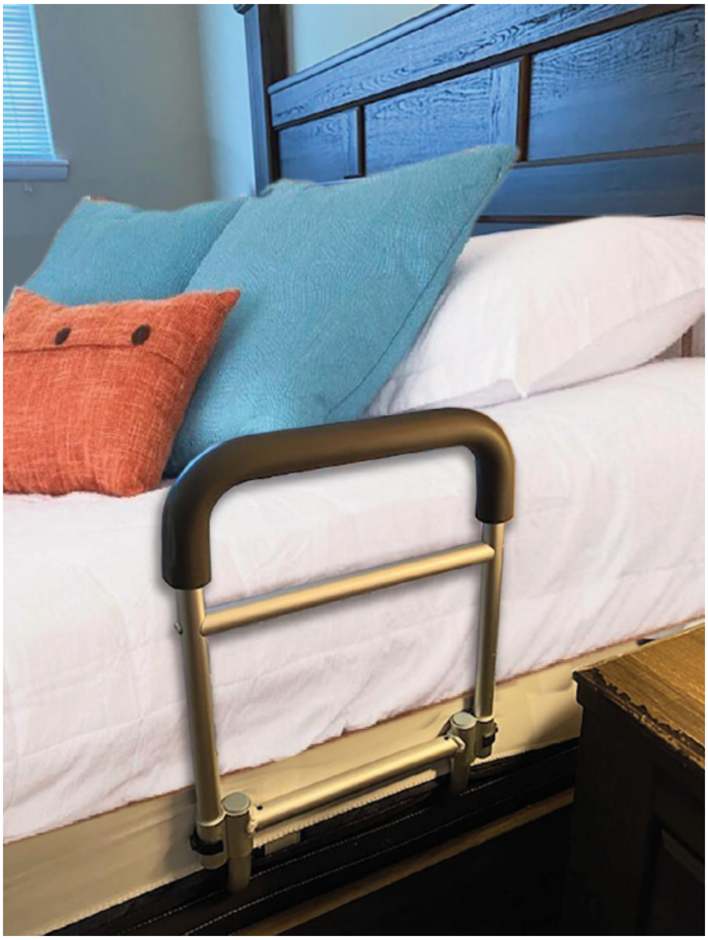
Appliance knobs can be marked at standard settings with these raised bumps. Use them on washer/dryers, microwaves and ovens.

BEDROOM

Beds come in all types and sizes, just like the people who sleep in them. The height from the floor to the top of the mattress significantly impacts the ease with which one can get on and off the bed. Generally, the lower the height of the bed, the easier it is to get into. But here's the catch-22: the higher it is, the easier it is to get out of. Ideally, when sitting on the edge of the bed with knees bent at 90 degrees, feet should rest flat on the floor. For the easiest transfers getting in and out of the bed, the height from the floor to the top of the mattress should be around 22 inches. If a bed is too low, elevate it with risers that are available in most home goods stores. If the bed is too high, one option is to remove the rug rollers or wheels on the bed frame to effectively decrease the height by around 2 inches. Switching from a standard box spring to a shallow one could also help compensate for a too-tall mattress. Other options would be to use a frame that eliminates the need for a box spring

HANDY HELPERS: Bump dots *(left)* provide a tactile clue for the visually impaired and can be used on washer/dryers, microwaves and ovens; Bed safety rails *(right)* assist with sitting, standing and balance when getting out of bed.

Search "bed safety rails" for handles that help with moving around in bed and assist with sitting, standing and balance when getting out of bed.



BATHROOM

The first thing I look at is the toilet. So much angst surrounds the use of this porcelain receptacle, and for good reason: when you gotta go, you gotta go! While traditional toilets measure less than 17 inches in height, people with joint difficulty or muscle weakness have a much easier time getting on and off toilets with a height between 17 and 19 inches, often referred to as "comfort height" toilets. These are in accordance with Americans with Disabilities Act (ADA) standards and generally found only in newer construction. While many people opt to replace what was often the originally-installed toilet with one that is a more comfortable height, there are other less-costly options to make it higher and safer. Raised toilet seats come with and without arms, and a commode placed over a toilet also works well. Risers are easily installed; many are removable with adjustable knobs, and some are more permanent. Consult with an occupational therapist to determine the best setup.

If seat height is not an issue, another option is to add handles on either side of the toilet. The handles serve as an armrest and will provide a gripping surface to help push up off of and lower down onto the toilet.

I next look at the existing type of shower or tub. The best scenario is a walk-in, zero-threshold shower with easily reachable faucets, and grab bars around the entire perimeter, both vertical and horizontal. A girl can dream, can't she? Most falls occur in the bathroom due to slippery floors and transfers and installing grab bars can

STEP RIGHT UP: *(Above)* To increase staircase safety, extend railings on both sides past both the top and bottom steps.

often help to prevent this. Grab bars come in all sizes, are available angled and straight, and are made of various metals and plastics. If using them inside the shower or tub, I recommend textured ones that do not become slippery when wet. A 24-inch vertical grab bar on either end to grab on to when entering the tub and a 36-inch horizontal grab bar across the back wall will suffice. Installation should be done by someone experienced in drilling into a shower wall. The height of the bar is dependent on the client's abilities and needs.

If a person is concerned with balance or does not have the endurance or ability to stand, there are a variety of seats and benches made for showers or tubs to make those environments safer.

Regarding using bathmats, try the "Shrager twist test" to determine if the rug is safe. Simply step on the rug with your feet about 12 inches apart, wiggle your hips, and try to do the twist. Music is optional. If the rug moves under your feet, it is not safe. A secure mat requires good rubber backing that will keep it in place and make exiting the shower safer.

STAIRS

To increase staircase safety, install railings on both sides and extend them past both the top and bottom steps. The transition from the last step onto the landing can be difficult, and the extended railings offer extra support in both directions. Good lighting is essential on staircases. As we age, our vision gets worse, and it becomes more difficult to discern where one step ends and the next begins. If stairs can't be navigated a stairlift can be installed.•

ABOUT THE AUTHOR:

Lynda Shrager is a registered occupational therapist with a Master's degree in social work and is a certified aging in place specialist. She is the CEO of At Home for Life, a business that helps seniors safely and successfully age in place. She authored Age in Place, A Guide to Modifying, Organizing and Decluttering Mom and Dad's Home. (Bull Publishing, 2018). Lynda presents workshops on all aspects of aging. Learn more at otherwisehealthy.com

TRY THIS : FAVORITES HACKS FOR HEALTH & HOME

THE EXTERIOR

- House numbers should be big, contrast with the exterior color, and be easy to read and locate. This is especially critical should first responders need to find your house.
- If expecting guests, keep the automatic garage door opener with you in the house. You can let people in without getting up to go to the door.

LIVING AREAS OF THE HOME

- When choosing lighting fixtures, purchase ones that use 3-way bulbs so that you can increase the lighting using a single switch.

THE KITCHEN

- The kitchen sink is an option for those who have difficulty accessing the tub or shower. Place a tub chair in front of the sink to facilitate a nice sponge bath. Fill a spray bottle with warm water for a mini shower.
- One-handed cutting boards exist with spikes to hold food for cutting and corner pieces to secure bread for spreading.

- Place a pants hangar over a cabinet knob and use the hooks to secure a recipe for easy viewing.

THE BEDROOM

- Over-the-bed tables are not just for hospital rooms. These provide a handy, adjustable-height surface that can hold needed items next to the bed. These tables also work well in any room of the house.

THE BATHROOM

- A thick, thirsty terry cloth robe to put on after bathing will absorb most of the moisture, making drying off easier.
- For the memory impaired, use automatic night-lights to illuminate the path to the bathroom.
- Place needed bathing items in a bin within easy reach.

- My favorite bathroom tip: Take a lady's stocking or pantyhose and cut a leg off. Place a bar of soap in the foot and tie the "soap on a rope" to the towel bar or grab bar in the tub or shower. Wash yourself right though the stocking and never drop the soap again!

ACCESSIBLE HOMES

A LOOK AT COMMUNITY-BASED HOUSING FOR ADULTS WITH DISABILITIES

LIVE AND BREATHE: Selecting the best place to live takes careful consideration for most people, but until recently this consideration has not been afforded to adults with disabilities..

BY MARY A. HOUSER, ED.D.

Parents have a lot to think about as their children grow up. There are the typical parental concerns such as how will my child do in school? Will he make friends? What career will he choose?

Parents of children with disabilities, however, often have additional concerns about their child's maturation than their typical counterparts. Perhaps one of the greatest areas of concern for exceptional parents is where their child will live as an adult after they pass away or when they are no longer able to care for him.

From the time a child with a disability is young, their parents begin to think about what life will be like for him as he grows older. Will he be able to live independently? Hold a job? What will he do for leisure activities? These realities can rest heavy on the minds of parents. Today in the United States, there are approximately 61 million individuals living with some type of disability (CDC, 2021). Examples of disabilities include autism spectrum disorder, intellectual impairments, and physical disabilities to name a few. The extent to which a person is impacted by his disability ranges from mild to severe and will have a lasting impact on his ability to function as an adult and the extent to which support will be needed for him to be successful and happy.

Selecting the best place to live takes careful consideration for most people. Historically, however, this consideration has not been afforded to adults with disabilities. In fact, housing options for adults with disabilities once painted a grim picture. To illustrate, in the mid-1800s, adults with disabilities were forced to live in psychiatric institutions which were segregated environments apart from their typical peers and families. This paradigm was referred to as the "institutional care model" and was the primary option for this population of people. It was common for medical doctors to recommend these state public hospitals to parents of children with moderate to severe disabilities for their long-term housing needs. These living environments were horrendous. Frequent reports indicated they were overcrowded, understaffed, and filthy places in which to live and the conditions often led to the abuse of individuals with disabilities.

Originally, it was thought that these institutions would serve as "training schools" for adults with disabilities. The hope was, under this model, adults with intellectual disabilities could be trained to perform basic living skills that would increase their ability to become part of their communities. The sad reality was that the number of individuals with disabilities was increasing rapidly, and institutions had difficulties keeping up with the demands they set forth. Ultimately, these institutions became custodial living arrangements instead.

Institutionalization for adults with disabilities lasted for many years. During this time, the civil rights of individuals was disabilities were largely ignored. They had no input into how they lived or where they lived. In the not-so-distant past, a movement toward better inclusion of adult with disabilities began to emerge when the families of those living in institu-

WHERE THE HEART IS : COMMUNITY-BASED HOUSING OPTIONS

Different community-based housing options for individuals have been created. Each of these models offers a different style of living, depending on the individual and his family's preference.

LIVING AT HOME

The majority of individuals with disabilities will remain living at home with their families in their adult life. The family home may be sometimes modified to create a more private space for an adult with a disability. For example, a family might create an addition to their home specifically for their adult child. Remaining in the family home is a good option for some because the ownership of the home might change over time so that the individual with a disability becomes the homeowner of the dwelling once his parents are no longer living. In this arrangement, the adult with a disability will typically have a support person living with him to help him with his daily needs.

INDEPENDENT LIVING

Independent living occurs when a person with a disability lives independently in a home or an apartment, and might even have a roommate. In this living arrangement, the adult with a disability does not require direct supervision and can successfully manage his daily living needs. Sometimes, individuals receive ongoing training to help enhance their independent living skills.

SUPPORTED LIVING

Supported Living. Supported living refers to a wide range of support needs adults with disabilities may need to retain their independence by being supported in their own home. This community-living arrangement is for individuals who want to live in their own apartment or home (rented or owned), but are unable to do so without the help of a support person. Support services are highly customized and can meet the needs of a wide variety of adults with special needs.

ADULT FOSTER HOME

Also known as Adult Family Care. In an adult foster home, the individual with a disability lives with a family other than his own, who has been trained to provide the appropriate supports he needs for his daily living. Examples of supports include bathing, eating, transferring and mobility, and housekeeping. Adult foster homes are usually managed by an agency or a private provider.

GROUP HOME

Group Home. This group home living arrangement has typically three to six adults with a disability who live together in one dwelling. This model is most similar to the institutions of the past in that individuals with disabilities only live with others with disabilities. Typically, however, residents are able to make decisions they would not be afforded in an institutional setting. Group home personnel assist residents 24 hours a day, 7 days a week, in meeting their individual needs. This housing options is typically operated by an agency or private provider.

SUPERVISED APARTMENT

Supervised Apartment. This semi-independent living arrangement occurs when an individual with a disability lives in his own home or apartment but needs more direct and intensive supports than the supported living model. A supervised apartment typically offers support services 24 hours a day, 7 days a week, if needed. Functional skills to support independent living such as cooking, banking, and community involvement, are often taught.

GROUP LIVING/OWNERSHIP (CO-OP)

Group Living/Ownership (Co-op). This living arrangement is similar to that of a group home, except the home is privately owned or rented by a group of individuals who have come together and formed a cooperative agreement. Often times, families of adult children with disabilities will enter into an agreement where they cooperatively select both the dwelling and the support services that will be provided to their adult children.

– Autism Speaks, 2020

tions wanted a better life for their loved ones. The history of deinstitutionalization occurred over many years and in many stages. The first notable change came about when states created small community programs and discharged adults with disabilities who were said to be responding well to antipsychotic medication and thought fit to live outside the hospital walls. Although many policies over the years have contributed to deinstitutionalization, it is worth mentioning a group of activists, known as the Independent Living Movement. From the 1960s to the 1980s, they worked tirelessly to put an end to institutional living. The results of their efforts are largely what is known as the community living model.

THE PURSUIT OF HAPPINESS: Several community-based models have emerged as the result of deinstitutionalization. No longer will adults with disabilities be denied their civil rights with respect to where they live.

In essence, the community living model permits adults with disabilities to live in the community of their choosing alongside their typical peers. Another major advancement in the integration of adults with disabilities came about as the result of a landmark Supreme Court case known as Olmstead v. LC (1999). This case determined that unnecessarily segregating individuals with disabilities was unlawful. The Olmstead v LC case centered around two adult women with disabilities who felt they were being unfairly kept in an institution and believed they could get better services in the community than in an institution. It was as a result of this court case that the Olmstead Act was born. This act subsidizes individuals with disabilities so they are able to live in the local community and receive state funds to finance their support services as opposed to living in an institution. The Olmstead Act has led to the closing of many institutions across the U.S.

In the past 20 years, community-based housing options for adults with disabilities have grown. In a true community-based housing model, adults with disabilities are not simply housed in local communities, but they are fully integrated into their communities and become an integral part of community life. In this model, adults with disabilities are afforded the same rights as their non-disabled peers. Examples of integration include being able to shop in the same stores at the same time as their non-disabled peers, and having the freedom to make choices about their own housing. Adults with disabilities are often provided support services to successfully live in the community through Home and Community-Based Services (HCBS) which is funded through Medicaid. Over the past years since the inception of The Olmstead Act, different community-based housing options for individuals have been created. Each of these models offers a different style of living, depending on the individual and his family's preference.

A common question about housing for adult with disabilities is, "How can it be paid for?" There are a few funding options. Options are largely based on eligibility and often vary from state to state. Some people will use private pay such as funds from their ABLE accounts or Special Needs' Trusts to help finance their housing. Other individuals who receive Supplemental Security Income (SSI) might put these funds toward their housing needs. There are also Section 8 Rental Vouchers which are made available through housing assistance programs at local housing authorities to help pay rent. Medicaid Home and Community-Based Service (HCBS) Waivers provide money to Medicaid beneficiaries to receive services in their own homes and community rather than in an institution (they do not pay rent, however).

Integrating adults with disabilities into neighborhoods is not only on the rise, but is now also the law. No longer will adults with disabilities be denied their civil rights with respect to where they live. Several community-based models have emerged as the result of deinstitutionalization. Hopefully, these are just the beginning of many more to come. •

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Dr. Mary A. Houser is an associate professor in the Department of Special Education at West Chester University of Pennsylvania. She teaches both undergraduate and graduate courses in foundations of special education, behavior management, autism spectrum disorder (ASD), language development, and family systems. She also serves as an educational consultant to The American College of Financial Services.

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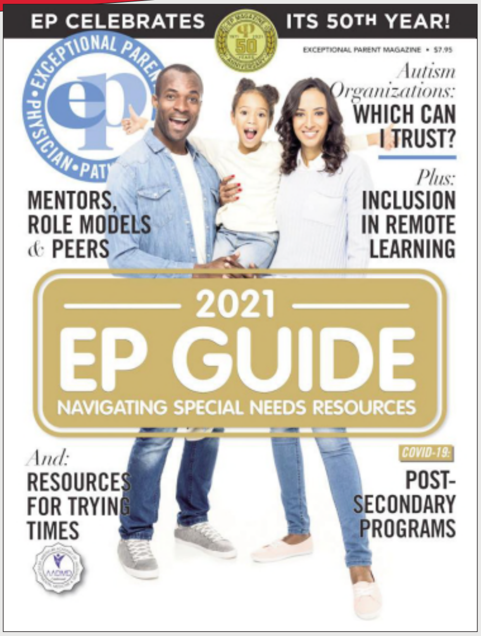

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ACCESSIBLE HOMES

THE ARC ON ACCESSIBLE AND AFFORDABLE HOUSING

[FROM THE ARC WEBSITE]

Being part of the community and living as independently as possible are among the most important values and goals shared by people with disabilities, their families, and advocates. A home of one's own – either rented or owned – is the cornerstone of independence for people with disabilities.

However, across the U.S., people with disabilities, including people with intellectual and developmental disabilities (I/DD), face a severe housing crisis. You can learn more about The Arc's position on housing by reading the organization's Position Statement within this article.

NO PLACE LIKE HOME: For people with disabilities, there are far too many barriers to housing. Without affordable, accessible housing in the community, many are at risk of institutionalization or homelessness.

WHY IT MATTERS

For people with disabilities, there are far too many barriers to housing. Without affordable, accessible housing in the community, many are at risk of institutionalization or homelessness.

Across the nation, many people with disabilities are experiencing an affordability crisis. Approximately 4.8 million (www.tacinc.org/knowledge-resources/priced-out-v2) non-institutionalized people with disabilities who rely on federal monthly Supplemental Security Income (SSI) have incomes averaging only about $9,156 per year – low enough to be priced out of every rental housing market in the nation.

Many people with I/DD live with aging caregivers (age 60 and older). As this generation of caregivers continues to age, many of their adult children with I/DD may be at risk of institutionalization or homelessness.

An accessible home offers specific features or technologies such as lowered kitchen counters and sinks, widened doorways, and wheel-in showers. For people who use mobility devices, finding housing with even basic accessibility features (e.g. an entrance with no steps) can be daunting, if not entirely impossible or unaffordable.

The availability of affordable, accessible housing remains far less than the need, leaving far too many people with I/DD institutionalized, homeless, or in “worst case” housing (www.huduser.gov/portal/sites/default/files/pdf/Worst-Case-Housing-Needs.pdf), i.e. paying too much in rent to afford other basics or living in severely inadequate conditions.

The Fair Housing Act (www.justice.gov/crt/fair-housing-act-2) prohibits housing discrimination on the basis of race, color, religion, sex, disability, familial status, and national origin. Complaints by people with disabilities often make up the majority of discrimination complaints (https://nationalfairhousing.org/wp-content/uploads/2018/04/NFHA-2018-Fair-Housing-Trends-Report.pdf) received by HUD’s Fair Housing Enforcement Office and other fair housing agencies.

WHAT IS THE ARC DOING?

People with I/DD have the right to live in accessible, affordable housing in the community. The Arc advocates to protect and improve federal housing laws and regulations and to ensure adequate funding for federal housing programs that assist people with I/DD and their families.

Public Policy Goals: The Arc’s Public Policy Goals (thearc.org/policy-advocacy/public-policy-goals) include many recommendations for improving access to affordable housing in the community.

Coalition Work: The CCD Housing Task Force (www.c-c-d.org/rubriques.php?rub=taskforce.php&id_task=8), which The Arc co-chairs, works with Congress and the Department of Housing and Urban Development (HUD) (www.hud.gov/topics/information_for_disabled_persons) to increase access to decent, safe, and affordable housing for all people with disabilities and to protect the rights guaranteed under the Fair Housing Act. The Arc is also a member of the Campaign for Housing and Community Development Funding (CHCDF) (https://nlihc.org/partners/chcdf) and a partner in Opportunity Starts at Home (www.opportunityhome.org).

KEY FEDERAL HOUSING INITIATIVES

Key programs at the U.S. Department of Housing and Urban Development (HUD) that seek to increase affordable housing for people with disabilities include:

Section 811 Supportive Housing for Persons with Disabilities Program: Section 811 is the only HUD program dedicated to producing affordable, accessible housing in the community for non-elderly, very low-income people with significant disabilities. See www.hudexchange.info/programs/811-pra

Section 8 Housing Choice Vouchers: HUD’s Section 8 Housing Choice Voucher program helps very low-income families, the elderly, and people with disabilities afford rental housing in the private market. About 1 in 3 households using Section 8 vouchers are headed by a non-elderly (under age 62) person with a disability. See portal.hud.gov/hudportal/HUD?src=/topics/housing_choice_voucher_program_section_8

National Housing Trust Fund: The National Housing Trust Fund (NHTF) is a new, dedicated fund that provides grants to states to build, preserve, and rehabilitate housing for people with the lowest incomes. See www.hudexchange.info/programs/htf

HOW YOU CAN HELP

There are many ways to advocate with and support The Arc’s grassroots movement.

Take Action: Join The Arc build a larger, stronger movement of people with disabilities, parents, siblings, and allies to advocate for the full inclusion and civil rights of all people. Take action now! https://p2a.co/IRPDZ5C

Act Now -Tell Congress to Pass the Better Care Better Jobs Act; Historic Investment in Disability Services: We need a groundswell of action – #MedicaidCantWait for this long-overdue support! https://p2a.co/IAFTwCz

For years, the service system that people with intellectual and development disabilities (IDD) and their families rely on, Medicaid, has needed an update. People are stuck on waiting lists, the direct care workforce is underpaid, and too often, unpaid family caregivers are filling in the gaps in service. The COVID-19 pandemic has magnified these problems and exposed the cracks and gaps in the care infrastructure when it comes to supporting people with disabilities.

Now, following the Administration's proposals, Congress has introduced the Better Care Better Jobs Act. This bill includes a long-overdue investment in the disability service system as part of a COVID-19 economic recovery to support care for Medicaid recipients and create more and better jobs for the workforce that provides that care.

We must ask Members of Congress to enact legislation that lives up to this plan and do more for people with disabilities, their families, and the direct care workforce. We need:

- ***Passage of the Better Care Better Jobs Act to fund expanded access to Medicaid HCBS*** *for people with disabilities on waiting lists and to address the direct care workforce crisis, including raising wages. This effort will also allow unpaid family caregivers who have been filling in the gaps of service for far too long to re-enter the workforce.*
- ***A national paid leave program.*** *The pandemic forced millions of people to choose between their own health, the health of their families, and their livelihood. We must invest in our care infrastructure and pass a national paid leave program that guarantees paid leave to family caregivers.*
- ***Improvements to the Supplemental Security Income program.*** *The lowest income people with disabilities who rely on SSI receive extremely limited benefits and cannot have more than $2,000 in savings, an amount that has not been updated since 1984. SSI benefits, asset limits, and other program rules must be updated to lift people with disabilities out of poverty.*

Act Now: Urge your Members of Congress to meet the needs of people with disabilities, their families, and the direct care workforce!

POSITION STATEMENT OF THE ARC AND THE AMERICAN ASSOCIATION ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES ON HOUSING

HOUSING

People with intellectual and/or developmental disabilities[1] (IDD), like all Americans, have a right to live in their own homes, in the community. Children and youth belong with families. Adults should control where and with whom they live, including having opportunities to rent or buy their own homes, and must have the freedom to choose their daily routines and activities.

ISSUE

People with IDD face a housing crisis with many contributing factors, such as a serious lack of safe, affordable, accessible and integrated housing, and significant housing-related discrimination. Outmoded public policy and programs which unnecessarily segregate people with IDD, as well as lack of coordination among funding systems, also pose major barriers.

Historically, families with a child with a disability had to either place their child in an institution, or manage without any supports or services at home. Institutions create an isolated, unnatural way of life that is inappropriate and unnecessary, while consuming a disproportionate share of limited public resources. As people with IDD have left institutions or their family homes, they frequently have been placed in group homes, often larger than family-sized, typically owned or leased by provider agencies. People in those settings may have little control over where and with whom they live, the services they receive, or the routines of daily life.

The recognition that people with IDD belong in the community has led to a growing demand for community-based housing. This demand is fueled by persons choosing to leave institutional settings, by young adults educated in inclusive schools, and by adults with IDD who live with elderly parents.

However, people with IDD are among the nation's poorest citizens. For many, Social Security and Supplemental Security Income benefits, which are often far lower than typical rents, are their primary or sole source of income; beneficiaries are generally priced out of rental markets across the country.

Affordable housing programs are drastically underfunded, with long waiting lists. In addition, Medicaid, the principal source of funding for services and supports for people with IDD, typically does not allow funds to be used for rent or other community-based housing-related costs. These factors pose major barriers to community living, making it difficult for people to move from segregated facilities into the community, and putting many people with IDD at risk of unnecessary institutionalization or homelessness.

POSITION

People with IDD have the right to live in safe, accessible, affordable housing in the community.

- People must have freedom, authority, and support to exercise control over their housing, including choice of where and with whom they live, privacy within their homes, access to flexible supports and services when and where they choose, choice in their daily routines and activities, freedom to come and go as they please, and housing that reflects their personal preferences and styles. Providers should honor individual choices and preferences.
- Housing should afford people with IDD the opportunity to interact with people without disabilities to the fullest extent possible.

SHARE YOUR STORY

What Supports Do You Need to Live in Your Community?Many people with disabilities rely on Medicaid-funded home and community-based services (HCBS) to live independently in their communities. HCBS supports people with disabilities by paying for things like employment supports, getting around, dressing, bathing or taking medication, and more.

Help advocate for HCBS by sharing YOUR story about the supports you receive to be as independent as possible or the supports you don't get but need to thrive. Share with The Arc AND your Members of Congress by answering 3 short questions!

We are looking for stories from people with disabilities, their families, and providers about:

- *Why HCBS is important to live the life you want to live in your community*
- *The importance of HCBS to your access to the community and the life you want to live*
- *Specific examples of how HCBS services support individuals to live independently*
- *Experiences with long waiting lists to receive HCBS*

Tell us about your life and what participating in the community means to you. We want to share why it's important for ALL individuals with disabilities to be integrated members of their communities. Visit **https://p2a.co/zc2H8lN** •

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ABOUT THE ARC

The Arc is a leader in disability rights and is the largest national community-based organization advocating for and with people with intellectual and developmental disabilities (I/DD) and serving them and their families: "We work tirelessly to uphold our vision that every individual and family living with I/DD in the United States has access to the information, advocacy, and skills they need to support their full inclusion and participation in the community throughout their lifetimes."

- The health and safety of people with IDD must be safeguarded wherever they live, but should always be balanced with the right to take risks and exercise choice and control.
- To ensure that people with IDD can make informed decisions about where and with whom they live, they and their families must be given understandable information about the benefits of living in the community, have the chance to visit or have other experiences in community settings, have opportunities to meet other people with disabilities who are living in the community, and have any questions or concerns addressed.
- All children and youth need a home with a family that provides an atmosphere of love, security, and safety.
- Adults with IDD should receive the supports they need to transition out of the family home when they wish to do so.
- Housing for people with IDD must be coordinated with home and community-based support systems, including transportation services, and should ensure access to other typical public resources.
- There must be adequate funding of services to support people to live in the community. Funding must be stable and not subject to arbitrary limits or cuts. People with IDD must not be subjected to unnecessary institutionalization or removal from their homes and communities due to state budget cuts.
- Public policy should promote small, typical living situations for people with IDD. Information about innovative housing models that promote independence should be widely disseminated.
- Housing for people with disabilities should be scattered within typical neighborhoods and communities, and should reflect the natural proportion of people with disabilities in the general population.
- Public funds must be shifted from restrictive institutional settings to community supports. Institutional settings and large congregate living arrangements are unnecessary and inappropriate for people with IDD, regardless of type or severity of disability.
- Affordable housing options must be available to people with IDD, including those with very low incomes. Affordable housing programs must be expanded and funded to eliminate long waiting lists. Public policies must ensure that people with IDD receive their fair share of all local, state, and national housing resources.
- Universal design and visitability[2] standards should be adopted for all new housing. New and significantly renovated multifamily housing should include fully accessible units in numbers that reflect the natural proportion of people with disabilities in the general population.
- People with IDD have the right to be free from housing discrimination, and there must be robust education, outreach, and enforcement of that right. People with IDD must have opportunities comparable to those of people without disabilities to rent or buy their own homes.

– Joint Statement with the American Association on Intellectual and Developmental Disabilities (AAIDD)

References

1. Intellectual Disability (ID) is a lifelong condition where significant limitations in both intellectual functioning and adaptive behavior emerge during the developmental period (before adulthood).

Developmental Disabilities (DD), first defined in 1975 federal legislation now known as "The DD Act", are a group of lifelong conditions that emerge during the developmental period and result in some level of functional limitation in learning, language, communication, cognition, behavior, socialization, or mobility. The most common DD conditions are intellectual disability, Down syndrome, autism, cerebral palsy, spina bifida, fetal alcohol syndrome, and fragile X syndrome.

The acronym "IDD" is used to describe a group that includes either people with both ID and another DD or a group that includes people with ID or another DD. The supports that people with IDD need to meet their goals vary in intensity from intermittent to pervasive.

2. Universal design means buildings, products and environments that are inherently accessible to both people with and without disabilities. Visitability is a set of construction standards through which housing offers a few specific accessibility features making it possible for people with disabilities to visit friends, family and neighbors.

EP LOOKS BACK: JULY 2012

Accessible Homes

BUILDING A BARRIER FREE HOME

Photos Courtesy of
Adaptive Architecture

Renovations on the house started in October 2011 and took six months. Plans included widening all the doors, removing walls, combining spaces, redoing the kitchen, and gutting all the bathrooms. In essence, the entire Mileti house is barrier free.

Gaby and Joe Mileti were living in their dream house, an English Tudor in New Rochelle, New York. They thought they would live in forever. It was the type of residence they pictured their two young children growing up in.

That is, until they received some devastating news six-and-a-half years ago that changed their lives forever.

When their son Joey was two and a half (who is now 8), Joe Mileti noticed that his son's hand was shaking when he tried to hold his bottle. The Miletis immediately made an appointment with their pediatrician, who referred them to a neurologist in New York City. It was at that appointment that they first heard about mitochondrial disease and how it would affect their son and his development.

"Joey was fine up until he was two and a half," recalls Gaby. "He made all of his milestones. He walked on time. He talked on time. He was great at kicking a soccer ball. There was absolutely nothing wrong. I'm a stay-at-home mom and I never noticed anything until my husband pointed it out one day.

"Our lives changed forever from that point on. The news was tragic," Gaby said. "That day is a nightmare that will be with me for the rest of my life. The doctors told us Joey had three months to a year to live. We were so devastated and shocked initially because we thought we were going to lose him any day. For the first year to year and a half after we heard, we lived with incredible anxiety. After a couple of years of him being stable, we knew we were not in any imminent danger and we had to make some changes."

Although Joey was still small enough that Gaby could easily lift him, the Miletis also have another son, Marco, just two years younger, that Gaby was also carrying around. "Marco was only one at the time, and I was carrying them both around the house. It was 12 steps just to get into the house, another 13 to get to their bedrooms, more if I had to go to the basement to do laundry – it was just too many," Gaby said. "I knew I couldn't do this forever, especially as they got older."

Mitochondria are responsible for creating more than 90% of the energy needed by the body to sustain life and support growth. When mitochondria cells fail, less and less energy is generated within the cell, resulting in cell injury and cell death. If this process is repeated throughout the body, whole systems begin to fail, and the life of the person in whom this is happening is severely compromised.

Since Mitochondrial Disease is progressive, affecting speech, fine motor skills and gross motor skills, the Miletis knew that life with their two sons would only become more difficult in a house with so many obstacles. "Our Tudor not only had a lot of stairs, but the hallways and doors were very narrow. Joey could barely squeeze by with his walker. We realized early on that we would have to make some radical changes to that house if we were going to stay, or we had to look for a ranch. And if we did stay in that house, even with renovating it, the house would never be really right for us."


The kitchen, dining room, and living room interior walls were removed to create one large open space with easy circulation.

So the Miletis began what turned into a two-year search for either property on which to build a house from scratch, or a ranch they could renovate. They also began their search for an architect who could help them achieve their goal.

“It’s a long, complicated process. It’s not only finding a ranch we could renovate, but finding one with minimal stairs upon entry and one on a flat piece of property. The last thing we needed was a ranch on a hill with a child in a wheelchair,” Gaby said.

As far as the architect, Gaby said her sister put her in touch with a family in her area with a special needs son, who then referred the Miletis to Adaptive Architecture, as they themselves had used the firm’s services to design a special needs home. Gaby said that while they interviewed numerous architects, it wasn’t until they met with the principle of Adaptive Architecture, Todd Rosenblum, that they knew they had found the right match.

“There are not too many special needs architects and initially I wasn’t specifically looking for one,” she said. “I just found Todd Rosenblum to be the most genuine and honest. He talked to us about our options of staying in the Tudor and renovating, or looking elsewhere. That’s when we came to the realization that we had to sell our house and look for something else.”

> JOEY WANTS TO GET AROUND ON HIS OWN AND THE BEAUTY OF THIS HOUSE IS THAT HE CAN

Gaby said that they looked at hundreds of houses, knowing that the most important thing was to find a house that would work for her so she didn’t have to do so much lifting and, for Joey, so he had easy access to every room.

The Miletis initially put in an offer on a piece of land so they could build from scratch, but they never heard back from the seller and decided to purchase a ranch to renovate instead. The 1965 ranch they found needed an extensive amount of updating and renovating, but Rosenblum told the Miletis that the house’s overall structure was one that he could work with.

Renovations on the house started in October 2011 and took six months. Gaby said Adaptive Architecture’s plans included widening all the doors, removing walls, combining spaces, redoing the kitchen, and gutting all the bathrooms. In essence, the entire Mileti house is barrier free.

Gaby said Joey is ambulatory, sometimes using a walker, and other times just maneuvering his body to get from point A to point B. “He wants to get around on his own and the beauty of this house is that he can,” she said. “He roams the entire house, which is something he couldn’t do in the old house.

She said her and Joe’s biggest concerns were ensuring the house did not in any way resemble a hospital or have a sterile feeling. What were the kitchen, dining room and family room were turned into one large great room. The two support columns were designed to look like architectural elements, and the bathrooms are what Gaby calls “magnificent.”

The accessible bathroom features a roll under sink and roll in shower.

In the garage, the original door was replaced with a wider accessible door, and the stair replaced with lift and new stair.

"By opening up the house, it enables me to see and hear the kids at all times. That was crucial for their safety," Gaby said. "It was critical in the design and layout, and in our meetings, I made that very clear to Todd. He understood where I was coming from, and went beyond our expectations."

Since the two boys share a bathroom, the Miletis wanted to make sure that it has all the features Joey requires, while still allowing Marco to feel like the space is also his. It was designed specifically to meet Joey's current and future needs – with a roll under sink, extra wide doors, open floor space, roll in shower with built in bench, decorative grab bars, anti-scald thermostats, and multiple shower heads.

"The bathroom for the boys is absolutely gorgeous. You would never know it's ADA compliant. It's very contemporaryt – similar to what you'd see in Europe," she said. "We wanted to give Joey a bathroom that would make him more independent and be easier for me when I have to be in there with him. We basically ripped out a 1965 purple bathroom and replaced it with a modern, sleek universal design that Adaptive Architecture created."

In order to deal with the five steps into the house from the garage, Adaptive Architecture incorporated a platform lift that Joey can use when he needs. The lift is located in a way that allows the Miletis to still park their car in the garage, keeping everyone – and the lift – away from inclement weather as they assist Joey in and out of the house.

Now that the project is complete, and the Miletis have settled into their new home, Gaby said she is glad that they were able to find an architect that specializes in accessible home designs. "If we had used a regular architect, I'm sure he would have been able to come up with the kitchen design, but the bathrooms and all the other unique aspects of a barrier free home can be quite challenging," she said. "I don't think just any architect would have nailed it. There's a lot you need to know and if you don't use someone who specializes in this area, you might not get what you really need.

"If I had to do this all over again, I would only use an architect who specializes in universal design because they know the ins and outs of what is needed for a special needs family. For example, Todd recommended that we install the structural support for a ceiling track system in Joey's bathroom in case we should need the lift down the road. I hope we never need it, but if we do, it will be easy to install. I don't think a typical architect would have thought of something like that," Gaby said.

Gaby said that no matter what road a family takes to create an accessible home – starting from scratch or renovating an existing home – it's most important to focus on aspects that will make the home visually appealing, while at the same time, meet the needs of both the disabled person as well as the entire family.

"I would highly recommend a specialty architect like Adaptive Architecture. Todd knew the nuances and all the right formulas to design a house that met our needs now and down the road," she said. "I'm hoping and praying every day that Joey's disease slows down, but at least we know we have a totally accessible home that will be here as we need it."

They just moved in on March 17, and Gaby said it's still so new — they are still getting used to it. She said: "We're creating memories here little by little."

And how does Joey feel about his new accessible home?

"His speech is very affected by his disease, but I can understand what he says. When Joey said 'Thank you for buying this house,' it was like we hit the lotto. Just hearing those words was amazing. It made all the anxiety of renovating worth it," Gaby said. "We do the best we can. It's all day by day."

The Miletis have started a research fund to help find a cure or treatment for Mitochondrial Disease called The JDM Fund for Mitochondrial Research. The website is www.thejdmfund.org. They can also be found on Facebook at **http://www.facebook.com/mobileprotection#!/pages/The-JDM-Fund-for-Mitochondrial-Research/ 329532960461031**

For information on accessible home design, contact Todd Rosenblum at Adaptive Architecture at 845-364-0337, info@adaparch.com, or visit www.adaparch.com •

READERS PLEASE NOTE: OUR WEBSITE IS NOW WWW.EPMAGAZINE.COM

EP's Innovative New Digital Strategy

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

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

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

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

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

"Our task is simple but abiding: working relentlessly for absolute, unabridged access to the fullness of community life for all people, most certainly people with IDD. This is my life's work, however imprecise and imperfect, and I'm fuller, smarter and more complete for the journey."

~ David A. Ervin, EP 2021 Advocate Hero

CONGRATULATIONS AND THANK YOU, EP MAGAZINE ADVOCATE HEROES!

50 FOR 50

50 YEARS OF EP • 50 ADVOCATE HEROES • PART II OF A SERIES

EP *Magazine*, formerly called *Exceptional Parent,* is celebrating its 50th anniversary of providing an award-winning forum for the disability community. With the recognition that it's the advocates who have provided the landmark events in the disability rights movement, *EP* is proud to honor 50 Advocate Heroes and showcase their extraordinary work and achievements in the following pages. While we have all had the opportunity to learn from those giants and pioneers that came before us, we are honoring living advocates.

Although it's safe to say that every parent of a child with complex disabilities is indeed an advocate, many of them have also distinguished themselves in advocating in a larger arena. Many of our showcased advocate heroes started out as parents, exceptional parents for sure. They combined their efforts in becoming teachers, therapists, counselors, lawyers, healthcare providers, researchers and activists. This special brand of advocates – along with all the others we honor – will always have a unique place in the disability movement, not only for what they have done, but also for those they have inspired.

On behalf of *EP Magazine*, its Editors, the EP Editorial Advisory Board, and a group of our peers in the disability field, we congratulate and thank our 50 Advocate Heroes for their tireless work in support of the special needs community. Our honorees will be featured in this and succeeding commemorative issues of *EP Magazine.*

JULIE BECKETT

"Advocating for people with special needs... I wake up every morning, thanking the good Lord that He sent Katie to me and then showed me the way to educate people about home and community services and their importance for all people, especially those on Medicaid!"

Julie Beckett, according to the Family Voices website, is the mother of Katie Beckett "who was the first Medicaid Home and Community-based Waiver child. The waiver was granted in 1981 and has become a vehicle for many persons with disabilities to receive care at home or in their communities. Katie passed away May 18, 2012. Ms. Beckett and Katie testified numerous times before Congress and worked on many projects in an advisory capacity for the Bureau of Maternal and Child Health, at the Department of Health and Human Services."

Ms. Beckett worked very closely with the U.S. House of Representatives and Senate. She carried out her work together with advocates from the health care community, the American Academy of Pediatrics, the Children's Hospital Group, Children's Defense Fund, who became great friends and allies. She helped found Family Voice's in the early 90's with her friends Polly Arango and Josie Woll, who were able to identify a parent in every state willing to help. They were volunteers before the passage of the Family Opportunity Act in 2005, establishing the Family-to-Family Health Information Centers. That now serve U.S. territories and Native American tribes.

Ms. Beckett believes she "was born to be a History teacher," and so became one. She loved that profession, but was offered a job at the University of Iowa that housed the Title V program, the Child Health Specialty Clinics, and it offered her daughter Katie health insurance, so she gave up her beloved profession. She worked for 30 years there, moving between the program and the Law school. She briefly worked on a SAMHSA grant, and then for the Centers for Disease Control in the National Center for Birth Defects and Developmental Disabilities. Ms. Beckett retired in 2014 from the University, fulfilled, knowing that her whole tenure was filled with helping kids and their families.

A LONG TENURE OF SERVICE: "I wake up every morning, thanking the good Lord that He sent Katie to me."

DAVID A. ERVIN, BSC, MA, FAAIDD

"For 34 years, I've had the privilege of walking alongside kids and adults with intellectual and developmental disabilities (IDD), at the heart of which is advocacy. Our task is simple but abiding: working relentlessly for absolute, unabridged access to the fullness of community life for all people, most certainly people with IDD. This is my life's work, however imprecise and imperfect, and I'm fuller, smarter and more complete for the journey."

ABSOLUTE ACCESS: "This is my life's work, and I'm fuller, smarter and more complete for the journey."

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

Mr. Ervin's current research interests include the impact of COVID-19 on people with IDD, health equity and cultural competence in healthcare delivery to people with IDD, and the impact of integrating multiple systems of care on health outcomes and quality of life. He was a contributing author to the Rubin, et al. seminal volume, *Health Care for People with Intellectual and Developmental Disabilities across the Lifespan,* and has authored or co-authored a number of peer-reviewed journal articles in 2019-2021 on health outcomes achieved by people with IDD through access to multidisciplinary healthcare models. He serves on a number of policy and practice committees, including the American Association on Intellectual and Developmental Disabilities, The Arc of the US Joint Committee on Long-term Services and Supports, and is on the Board of a Virginia community service provider association.

DAVID FRAY, DDS, MBA

"Growing up with a deaf father that cared about people with disabilities impacted my career and shaped my values. As a dentist, I sought to serve life as whole rather than focus on the need to fix teeth that may seem broken. I have had the privilege of blending two vocations, that of a health care provider and a government disability director. The inclusive journey for individuals with developmental disabilities and their families continues to lead us as a society to make us better. My deepest hope is for future leaders in healthcare to listen to people with developmental disabilities and dare to dream with them and their families to achieve healthy and enriched lives. It is with gratitude that I have been honored and with understanding that we all stand in the footsteps of progress of those that mentored and inspired us. Dr. Steve Perlman has been my mentor for decades. There are many others. But the person that impacted me the greatest is Paula, my friend."

Dr. David Fray graduated with a DDS from UTSD Houston in 1979 and received his MBA with an emphasis in Healthcare Administration from Oklahoma City University in 1997. He served for 16 years as a public health administrator in two States as Developmental Disabilities Director after 15 years of a private dental practice with an emphasis on geriatric and adult special needs care. He is board certified in Long-term Care from the National Association of Boards and is a licensed Long Term Care Administrator. He holds a mini-residency certificate in Developmental Dentistry from the University of Louisville School of Dentistry and Lee Specialty Clinic in Louisville Kentucky and a master's certificate as a Certified Healthcare Emergency Planner (CHEP certification). Dr. Fray currently teaches at the University of Texas School of Dentistry in Houston Texas.

He was Chief of the Developmental Disabilities Division (DDD) in the Hawaii Department of Health in Honolulu for 13 years. While there. the Division eliminated all waitlists and moved all services to community based self-determined outcomes. The United Cerebral Palsy (UCP) Annual Inclusion Report has consistently ranked Hawaii as a top-five state for inclusion in community services with high quality outcomes. As Chief of the Developmental Disabilities Division in the Hawaii Department of Health from 2002 until 2014, he administered statewide comprehensive health and community support services to persons with intellectual and developmental disabilities. Dr. Fray is the immediate Past President of the American Academy of Developmental Medicine and Dentistry (AADMD) serving on the AADMD Board. He is a private pilot and scuba diver. He and his wife, Judy, are the proud parents of two adult children and grandparents to four grandchildren.

FOOTSTEPS OF PROGRESS: "The inclusive journey for individuals with developmental disabilities and their families continues to lead us as a society to make us better. My deepest hope is for future leaders in healthcare to listen to people with developmental disabilities and dare to dream with them and their families to achieve healthy and enriched lives."

RICK GUIDOTTI

"Around the globe, no matter where I'm shooting, no matter which continent we are on, which language we are speaking, people everywhere share the need to Be Seen, Be Heard and Belong! Change How You See, See How You Change!"

Rick Guidotti, an award-winning photographer, has spent more than 20 years collaborating internationally with nonprofit organizations, hospitals, medical schools, educational institutions, museums, galleries, advocacy groups and communities to effect a sea-change in societal attitudes towards individuals living with genetic, physical, behavioral or intellectual difference. His work has been published in newspapers, magazines and journals as diverse as GQ, People, the American Journal of Medical Genetics, The Lancet, Spirituality and Health, Atlantic Monthly and LIFE Magazine.

Mr. Guidotti is the founder and director of Positive Exposure, a nonprofit organization that promotes a more inclusive world through photography, film, and educational programs. It has significantly impacted the field of human rights, mental health, medicine, and education by providing new opportunities to see each individual as a human being and valued member of our society.

In June 1998, his work was featured in LIFE Magazine's cover story entitled, *Redefining Beauty.* In collaboration with the Genetic Alliance and the National Human Genome Research Institute, Mr. Guidotti premiered a photographic exhibition for the People's Genome Celebration at the Smithsonian's Museum of Natural History in 2001. Since then, he has continued to develop exhibitions, lectures, workshops, educational programs and initiatives around the globe. Examples: The FRAME series (Faces Redefining the Art of Medical Education), a web-based film library that changes how medical information is presented to healthcare providers in training, clinicians, families and communities. PEARLS Project highlights our shared humanity by providing a blog platform where individuals from around the world can tell their stories, and allow audiences to experience life from their unique perspective.

CHANGING HOW WE SEE: "People everywhere share the need to Be Seen, Be Heard and Belong"

Mr. Guidotti is the focus of the award-winning documentary, *On Beauty,* by Kartemquin Films. In 2019, Rick and his team opened their new headquarters in East Harlem on New York City's Museum Mile that embraces individuals at risk of stigma and exclusion, and serves as a central hub for showcasing the work of visual, performing, literary and multisensory artists, as well as providing educational, cultural and artist-in-residency programming. He remains committed to collaborating with individuals, families and communities around the world, "celebrating the beauty and richness of our shared humanity.

MATTHEW P. (MATT) JANICKI, PH.D.

"It has always been my interest to produce and support the underlying empirical basis for much of what we do with disability advocacy and provision. I was fortunate to hold a career position with a state developmental disabilities agency which supported my interests, exposed me to what adults with disability faced, stimulated my ability to develop new program models, provided the environment for building a strong network of others with similar interests, and helped with expanding research in support of the programs we were undertaking. I am fortunate, even now after entering academic life, to be effective in undertaking both advocacy and expanding the science which frames the supports for addressing age-related disabilities."

GRACE FOR THE AGED: "I am fortunate to be effective in undertaking both advocacy and expanding the science which frames the supports for addressing age-related disabilities."

Matthew P. Janicki, Ph.D. is the Co-President of the National Task Group on Intellectual Disabilities and Dementia Practices, a non-for-profit engaged in advocacy on behalf of adults with intellectual disability affected by dementia. He is also a research associate professor in the Department of Disability and Human Development at the University of Illinois at Chicago, and a member of the federal Advisory Council on Alzheimer's Research, Care, and Services (under the US National Alzheimer's Project Act).

Previously, Dr. Janicki was the director for aging and special populations for the New York State Office for People with Developmental Disabilities, and spent a year as a Joseph P. Kennedy, Jr. Foundation's Public Policy Leadership Fellow at the National Institute on Aging and the United States Senate. Currently, he is leading a longitudinal study of specialized group homes designed for dementia-related care of adults with intellectual disability, including Down syndrome. He was the principal investigator of several federally-funded studies that examined how community agencies provide community supports to adults with intellectual disabilities affected by Alzheimer's disease and how families are aided by community agencies in supporting adults with Down syndrome affected by Alzheimer's disease. He was also the project director of a NIH-funded effort that provided the World Health Organization with a series of background reports on promoting longevity among adults with intellectual disabilities throughout the world. He was the founding editor of the *Journal of Policy and Practice in Intellectual Disabilities* and is also the editor of numerous books and author of articles on aging, dementia, public policy, and rehabilitation concerning adults with intellectual and developmental disabilities (including *Dementia, Aging, and Intellectual Disabilities: A Handbook*).

BARBARA L. KORNBLAU, JD, OTR/L, FAOTA

"Advocacy to me means looking at how things should be for everyone – not just 'able-bodied people' – and spreading the word through organizing and collaborating with others with common interests in equal access to the world we live in, the services we depend on, and the opportunities in which we should all be able to participate – from advocacy for education, to housing, to healthcare, to employment, to community access, and community integration."

STRATEGIES FOR INCLUSION: "Advocacy means spreading the word through organizing and collaborating with others with common interests in equal access to the world we live in."

Barbara L. Kornblau is an attorney, an occupational therapist, a former President of the American Occupational Therapy Association (AOTA), a certified case manager, a certified disability management specialist, a person with a disability, the mother of six now-adult children with disabilities, and a national disability rights advocate. When the Americans with Disabilities Act (ADA) first became the law of the land, Ms. Kornblau prepared the White Paper for AOTA to educate its members on their advocacy role under the new law. As a former Robert Wood Johnson Health Policy Fellow in the U.S. Senate, she worked on disability issues for Senators Harkin and Rockefeller. Following this Fellowship, she served as a government relations and health policy consultant to Special Olympics International and the American Association of People with Disabilities.

Wanting to ensure that people with disabilities were integrated into the Affordable Care Act (ACA), Ms. Kornblau organized and led a coalition of National, State, and Local disability organizations to advocate for the integration of people with disabilities throughout the bill. Through inclusion of all people with disabilities and evidence-based sign-on letters, they succeeded in getting the word "Disability" included in the Affordable Care Act, everywhere the words "Racial" and "Ethnic" appeared.

After ACA became the law of the land, she saw that some of the disability provisions were being ignored. She was told there was no evidence to support people with disabilities as an underserved population, even though this was specified in ACA. She organized the Coalition for Disability Health Equity, led this coalition of disability self-advocates, public health and disability researchers, disability policy experts, disability public health organizations, data experts, and disability advocacy groups, to collaboratively respond. She developed a strategy, and as a result of the compiled key data and evidence of the existence of disability health disparities, successfully negotiated with high-level HHS leadership. This resulted in HHS' commitment to an action plan to end disability health disparities, on the same basis as racial and ethnic groups.

Ms. Kornblau has spoken on disability-based health disparities at the intersection of race and ethnicity as a panelist at several Congressional briefings as part of her role representing "disabilities" on the Health Equity and Accountability Act (HEAA) Steering Committee, which now recognizes that "intersectionality" includes people with disabilities.

JOSEPH M. (JOE) MACBETH

UNENDING EFFORTS: "While this advocacy is my life's work, it is just a small part of doing what's right and just for people with disabilities."

"I was hired as a direct support professional after two days of orientation, directly after graduating from college. I will never forget how unprepared I was to support people with significant and complex disabilities and medical complications. Sadly, nearly 40 years later, this hasn't changed much and an unprepared, untrained and unprofessional direct support workforce is our system's greatest vulnerability. While this advocacy is my life's work, it is just a small part of doing what's right and just for people with disabilities. We have much more work to do and this advocacy will never end."

Joseph M. Macbeth is the Chief Executive Officer of the National Alliance for Direct Support Professionals (NADSP). He was the first employee hired by the organization in 2011 and has brought it to national prominence. He has worked in the field of intellectual and developmental disabilities for nearly 40 years, beginning as a Direct Support Professional.

In addition to authoring and co-authoring several publications regarding workforce issues, volunteering for non-profit boards of directors, and creating a nationally- recognized certification model using digital badges, Macbeth was appointed by New York Governor Andrew Cuomo as a Member of the Advisory Council for the New York State Justice Center for the Protection of People with Special Needs. In 2020, he was added as an honoree for the 20th Anniversary Historic Recognition Project sponsored by the American Association on Intellectual and Developmental Disabilities (AAIDD) recognizing distinguished leaders in the field.

TEMPLE GRANDIN PHOTO BY ROSALIE WINARD

JOHN MCGINLEY

"My mission in the Special Needs Community is to advocate for those, who cannot advocate for themselves. My son Max McGinley, was born with Down syndrome. And Max has served as a gateway and a blessing. Through Max, I have been lucky enough to know and love, countless individuals who were also born with Down syndrome. Our collective journey is all about inclusion, kindness and acceptance. We are only beginning to see the light."

John C. McGinley, is remembered by many as an actor for his roles in the TV show Scrubs, as well as in Office Space, Wall Street, and Platoon. In the special needs community, however, Mr. McGinley is recognized as a passionate advocate for people with Down syndrome. He was recognized as Parent of the Year by iVillage.com. In 2011, he received the Quincy Jones Exceptional Advocacy Award for his work on behalf of people with Down syndrome, and people with developmental disabilities in general.


BEGINNING TO SEE THE LIGHT: "Our collective journey is all about inclusion, kindness and acceptance."

Mr. McGinley is a Board Member and International Spokesperson for the Global Down Syndrome Foundation. In addition, he has been a Special Olympics Global Ambassador and was an integral part in crafting Special Olympics' "R-word: Spread the Word, To End the Word" campaign. In his interview with *EP Magazine* in 2008, John shared this advice to new exceptional parents who learn that their child has Down syndrome: "Number one," John said, "you didn't do anything wrong. First and foremost, this is not reciprocity for any transgressions that you may have done when you were younger. You didn't do anything. The kid has an extra 21st chromosome. That's it. That's number one. Number two: breathe. Get some air, because it's going to be a while. Number three: start discovering stores of patience that you didn't know existed within yourself. Because some things – reading, writing, walking, holding your hand, having a catch – are going to take a little longer. So, if you can find a container with patience and sprinkle it generously over your Wheaties in the morning, do it."

MARGARET A. NYGREN, EDD

"The most fundamental aspect of social justice is the assurance that all people can access the essential building blocks – supports, education, healthcare, community, civil rights – for creating their best lives."

Dr. Margaret A. Nygren has served as the Executive Director and CEO of the American Association on Intellectual and Developmental Disabilities (AAIDD) since 2010. Previous roles include positions at the Association of University Centers on Disabilities (AUCD) and a Fellowship in the Disabled and Elderly Health Programs Group at the Centers for Medicare & Medicaid Services (CMS) in Baltimore.

During her tenure at AAIDD, Dr. Nygren has worked to advance awareness of effective strategies to improve the inclusion and quality of life of people with IDD through the organization's publications, educational events, and public policy activities. Since 2011, she has organized annual international delegations to promote knowledge transfer and exchange among disability professionals, researchers, and policymakers of many countries. She has delivered invited presentations at national and international conferences hosted by the leading organizations in IDD. She has testified before committees of the U.S. Food and Drug Administration on electric shock devices, and the United Nations on barriers to deinstitutionalization, and she contributed to the deliberations of the committee of the World Health Organization charged with drafting the "Disorders of Intellectual Development" entry in the forthcoming 11th edition of the *International Classification of Diseases (ICD-11).*

Dr. Nygren serves on the editorial board of the journal *Health Psychology Report* and as a reviewer for *Intellectual and Developmental Disabilities.* Representing AAIDD, she works closely with national partners to advance a shared legislative agenda, and with The Arc of the United States, to develop effective position statements on issues that are important to people with IDD and their families.


STRONG FOUNDATIONS: "The most fundamental aspect of social justice is the assurance that all people can access the essential building blocks for creating their best lives."

She currently serves on the following national advisory committees: the Down Syndrome Consortium of the National Institute of Child Health and Human Development (NICHD), the Institute for Exceptional Care, the Residential Information Systems Project of the University of Minnesota, and the Transit Planning 4 All project of the Transportation Association of America.

A Fellow of the AAIDD, Dr. Nygren earned a bachelor's degree from Beloit College, a master's degree from West Virginia University, and a doctorate from Nova Southeastern University; and she recently completed a certificate in diversity and inclusion from Cornell University.

ELIZABETH A. (LIZ) PERKINS, PHD, RNLD, FAAIDD, FGSA

A CALLING TO IMPROVE LIVES: "It is simply my duty to amplify the needs and the voices of all people with disabilities while demanding the respect we all deserve."

"Advocacy is the ultimate expression of my education and passion for social justice and health equity. If anything I have said, done, written, or taught, has improved the quality of life for people with IDD and their caregivers, or helped the professionals that support them to do their job better, then that makes me happy. As a professional with a disability in the disability field - it is simply my duty to amplify the needs and the voices of all people with disabilities while demanding the respect we all deserve."

Dr. Elizabeth A. Perkins is the Associate Director and Research Associate Professor at Florida Center for Inclusive Communities-UCEDD, University of South Florida (USF). Originally from England, Dr. Perkins is a congenital above-elbow amputee. She became one of the first nurses in the UK with this disability to qualify and practice as a Registered Nurse Learning Disabilities (RNLD; learning disabilities is the UK term for intellectual disabilities). Her clinical career has focused on health and long-term care in older adults and people with intellectual disabilities. She emigrated to the USA in 1998, where she returned to higher education, earning a BA in Psychology (*summa cum laude*) and a PhD in Aging Studies from USF. Dr. Perkins is a Past President and Fellow of the American Association on Intellectual and Developmental Disabilities, and a Fellow of the Gerontological Society of America.

Dr. Perkins' academic career has concentrated on improving quality of healthcare for people with disabilities, as well as aging with disabilities, and caregiving research. She leads FCIC's Florida DD Waitlist Campaign to raise awareness of the extensive waitlist for DD Medicaid Waiver services in the state. She also teaches a graduate class, "Issues and Trends in Developmental Disabilities," and mentors graduate students, including medical students, as part of FCIC's Interdisciplinary Training Program. Dr. Perkins' research and scholarly work has been published in a variety of notable journals including the *Journal of the American Medical Association.* She co-authored the 5th, through the 7th editions of *Physical Change and Aging: A Guide for the Helping Professions,* a highly regarded gerontology textbook. In addition, Dr. Perkins developed popular health advocacy resources and tools, including the popular My Health Passport, and My Health Report. She introduced the term "compound caregiving" and subsequent research to identify the unique needs of lifelong caregivers of adult children with DD, who also become caregivers to other family members. Dr. Perkins is an editorial board member for the journal Inclusion, and one of the first international editorial board members of *Learning Disability Practice,* a journal of the UK's Royal College of Nursing.

Dr. Perkins was a recipient of the Rosalynn Carter Institute for Caregiving/Johnson & Johnson's Mattie J. T. Stepanek Intergenerational Caregiving Scholarship. In 2020, Dr. Perkins was recognized as a National Honoree in the National Historic Recognition Project. Recipients of the National Honors were recognized for their significant national contributions to or impact in the field of IDD in the U.S.A. between 2000 and 2020.

MARIA SHRIVER

"To me, advocacy means caring about those with special needs. It means using my voice, my time, and my energy to make sure they can use theirs. It's that simple. Whatever I can do, I'd like those with special needs to do. Whatever dreams I have for my children, I'd like the same ones for those parents and their kids. I envision a world where all of us are special and all of our needs are met."

ARCHITECT OF CHANGE: "Whatever I can do, I'd like those with special needs to do."

Maria Shriver is a mother of four, an Emmy and Peabody award-winning journalist, a seven-time New York Times best-selling author, an NBC News Special Anchor and the founder of the nonprofit The Women's Alzheimer's Movement.

Always curious about the world, Maria has devoted her life to reporting and interviewing some of the biggest changemakers of our time. In addition to her work for NBC News, she is also the founder of the media enterprise Shriver Media, which produces award-winning documentaries and films, bestselling books, and a beloved popular weekly email newsletter called *The Sunday Paper.*

Shriver's life and career are driven by her fervent belief that everyone has the ability to be an "Architect of Change" and move humanity forward in their own way. Her latest book, *I've Been Thinking...* and its new companion *I've Been Thinking...The Journal* – both which were instant bestsellers – were created to offer wisdom, guidance, and inspiration to those seeking to create a meaningful life of their own.

PHOTO OF MARIE SHRIVER PROVIDED BY CYDNEY WEINER

MARK WOLFF, DDS, PHD

"Throughout my 40 years in practice, I have made it a priority to consider the needs of persons with disabilities, many of whom have expressed how difficult it is to find a dentist willing and able to accommodate their needs. It is my firm belief that EVERY dentist should be able to provide care to persons with physical, intellectual, or developmental disabilities. It is thrilling as an educator to provide students with experiences serving persons with disabilities, so that we can demystify the process of providing care and create equitable access for all."

Dr. Mark Wolff is the Morton Amsterdam Dean of the University of Pennsylvania School of Dental Medicine and a Professor in the Department of Preventive and Restorative Sciences. He is a celebrated teacher, globally engaged scholar, and deeply experienced clinician. He is a prolific author, lectures worldwide, and is a frequent consultant to the dental industry. He has been a lifelong advocate and educator for individuals with physical, intellectual, and developmental disabilities through the lifespan.

Dr. Wolff holds both a DDS (1981) and PhD (1997) from the State University of New York (SUNY) at Stony Brook, where he also served on the faculty for more than two decades. Prior to coming to Penn, Dr. Wolff was Professor and Chair of Cariology and Comprehensive Care at New York University. He brought bold and innovative thinking to his role at NYU, where he led more than 400 faculty and staff. Among programs there, Dean Wolff designed and implemented the world's largest electronic dental-health record and fully digital imaging system. One of his final projects at NYU before coming to Penn involved building a new care center for persons with disabilities. He recently replicated that project at Penn where a new 3,500 square foot Personalized Care Suite provides preventive and interceptive oral health care for patients of all ages living with a disability. The Center features 12 dental operatories, and is outfitted to comfortably treat patients in wheelchairs and on gurneys. It includes a quiet room with low lighting and sound baffling for patients with sensory sensitivities. A key goal of the Center is to educate students as well as practicing clinicians, teachers, nurses, and caregivers on how preventive practices and teamwork can improve the quality of life for both people with disabilities and their families. Other initiatives Dr. Wolff has launched at Penn include a major expansion of the school's community dentistry programs in West Philadelphia, and creation of a new policy center, the Center for Integrative Global Oral Health, that is working to craft creative solutions to address unmet oral health needs related to the worldwide prevalence of caries, periodontal disease, oral cancer and craniofacial deformity which impacts more than 3-billion people annually.

DEMYSTIFYING THE PROCESS: "It is my firm belief that EVERY dentist should be able to provide care to persons with physical, intellectual, or developmental disabilities"

ALLEN WONG, DDS, EDD

"Advocacy is the responsibility of everyone. We cannot stand by and watch injustice go unanswered. Our Hippocratic Oath guides us as healthcare professionals to 'do no harm' and in that we need to stand up and speak up for those that cannot. Our AADMD motto of 'One Voice for Inclusive Health' helps us to rally like-minded organizations and people to promote inclusive and equitable healthcare. Our small voices become large ones that reverberate and resonate to bring changes. I am energized by the many who advocate along with me in the pursuit of ending human suffering."

Early in his career, Dr. Allen Wong knew that it was important to provide his best dental care to all patients. During his residency, he had an opportunity to work with those with special healthcare needs (Intellectual Developmental Disability/IDD, medically- compromised, psychologically or physically-challenged as well). Hearing the stories of how challenging it was to find a provider from patients, let alone a good one, made him aware of the problem of access to care. Moreover, seeing the gross neglect of dental care for these populations was, to him, alarming. He has been on a mission since his graduation to encourage, teach, advocate and provide care for those with special healthcare needs. His volunteering with Special Olympics Special Smiles Program further elevated his passion to make a difference. Now, as Global Clinical Advisor, he has the privilege of promoting access to care and teaching prevention practices through dental caries and periodontal risk management with minimally-invasive strategies.

The American Academy of Developmental Medicine and Dentistry (AADMD) was the organization that helped elevate the advocacy, education and access to care for those with IDD. As President of AADMD, Dr. Wong feels privileged to help deliver the message and work towards equitable healthcare for all. His recent bout with COVID-19 in the Intensive Care Unit for four weeks made him acutely aware of the isolation and stressful procedures patients experience in the hospital. Those with IDD are two to four times more likely to contract COVID-19 and six times likely to die from it. This is another example of health disparity.

Building relationships, challenging healthcare students to join in the mission, increasing educational curriculum for medical and dental schools are part of Dr. Wong's mission. He says he feels blessed to have Pacific Dugoni Dental school, his dental school, support him in his various endeavors.•

VOICES OF JUSTICE: "I am energized by the many who advocate along with me in the pursuit of ending human suffering."

[PART TWO OF TWO]

A BRIEF HISTORY OF SPECIAL EDUCATION

MILESTONES IN THE FIRST 50 YEARS

BY ERNST VANBERGEIJK, PH.D., M.S.W. AND LINDA SHANDRICK LENGYEL, PH.D.

The Weast case may have left advocates disheartened, but a more recent case has them again celebrating. Although FAPE is the cornerstone of IDEA, and the first case to go to the Supreme Court "defined" ***appropriate education,*** *the definition lacked clarity and was interpreted differently throughout the country. Some say it was predictable that the Supreme Court would again grapple with the educational benefit standard put forth in the* Hendrick Hudson Dist. Bd. Of Ed. V. Rowley *case.*

In 2017, the court issued a unanimous opinion that provided a higher standard to determine whether the student's IEP was calculated to enable the student to make progress. The courts decided in *Endrew F. v. Douglas County School District* (2017) that making "some" progress was not a sufficient standard to apply in evaluating whether FAPE was provided and that the educational benefit standard needed to be more demanding. Drew's (short for

SETTING A PRECEDENT: Amy Rowley *(above)* was a deaf student, whose school refused to provide a sign language interpreter. Her parents filed suit contending violation of the Education for All Handicapped Children Act of 1975.

PHOTO HOWIE SWETZ/THE JOURNAL NEWS, WESTCHESTER, N.Y.

Endrew) parents challenged the school district's delivery of FAPE, stating that their son was not making adequate progress, given the supports and services provided under the direction of his IEP. When he was in fourth grade, they withdrew him from the public school and sent him to a private school where they saw an improvement in both his behavior and academic performance. They sought reimbursement for the tuition of the private school. The lower courts ruled in favor of the school district, stating that some benefit was evident, although the IEP contained repeated goals across the years and Drew had increasingly challenging behaviors with minimal academic progress.

SPREADING THE WORD: Barack Obama poses with Rosa Marcellino *(bottom)* and her siblings during the Rosa's Law signing ceremony in 2010.

PHOTO COURTESY REUTERS/JASON REED

The Supreme Court ruling raised the standard, indicating that some benefit was not sufficient as evidence of FAPE and that a higher or meaningful benefit must be used as the standard, stating that a "substantive standard was implicit in the Act" (as cited in Yell, 2020). As a result of this favorable ruling, Yell (2020) provides guidance to parents and advocates stating that IEP teams should "a) assess and analyze all of a student's unique educational needs; b) develop ambitious, meaningful, and measurable annual goals; c) rely on research-based special education procedures; and d) collect actual data and make instructional decisions based on the data" (p. 290). Parents and advocates can now go into IEP meetings requesting the aforementioned. It has been speculated that school districts will be at a greater disadvantage if they lack strong progress monitoring data that measures learning, or "educational benefit" (Yell, 2020). Additionally, school districts will have more accountability in making informed instructional decisions based on the data if they deem instruction is not working. Hopefully, the days of repeated IEP goals across several years are behind us.

The *Dracut School Committee v. Bureau of Special Education* found that a school district could be held financially responsible for compensatory education of a student even after the student had graduated from high school. The hearing officer found that Dracut did not provide a free and appropriate public education (FAPE) to the student in question. Further, the school district failed to provide the student with an adequate transition plan. The school district also did not compensate the parents' experts at reasonable rates of pay and were forced to compensate at a higher rate.

The Higher Education Opportunity Act of 2008 (HEOA) was an important milestone in inclusion of special needs individuals in higher education. HEOA governs Title IV, which is the Federal Student Aid Program. Prior to 2008, a student needed to be enrolled in a degree bearing program full-time in order to qualify for federal student aid. With the passage of HEOA, students with an Intellectual Disability or significant cognitive impairment who are enrolled in a Comprehensive Transition and Post-secondary (CTP) program are now eligible for Pell grants, Federal Supplemental Education Opportunity Grants (FSEOG), and Student Work Study monies. The CTP model requires that colleges and universities develop a curriculum specific to this population's needs with a specific advising structure AND that the students enrolled in the CTP be with their non-disabled peers at least 51% of the time. Students enrolled in a CTP do not have to purse a degree or certificate. Now, there are approximately over 200 CTPs across the country, which sounds like a large number, however, there are over 7,600 Institutions of Higher Education (IHE) that qualify for Title IV funding or Federal Student Aid. Although this represents only about 2.6% of all IHEs that have a Comprehensive Transition and Post-secondary program, it does represent a major step toward inclusion of students with disabilities in higher education.

> *"Although only about 2.6% of all Institutions of Higher Education have a Comprehensive Transition and Post-secondary program, it does represent a major step toward inclusion of students with disabilities in higher education."*

ROSA'S LAW

This law was passed unanimously by the Senate, approved by the House of Representatives, and signed into law by President Barack Obama on October 10, 2010. The law replaced the word "Mental Retardation" with Intellectual Disability (ID) in Federal laws. It reflected the fact that retardation had taken on a pejorative connotation in culture and no longer reflected the original medical/scientific usage. The use of the term Intellectual Disability (ID) is now the preferred term.

WORKING WONDERS: The Workforce Innovation Opportunity Act has been hailed as the most significant piece of legislation for people with disabilities since the Americans with Disabilities Act of 1990.

> *"Rosa's Law (Pub. L. 111-256) amended sections of the Rehabilitation Act of 1973, as amended (Rehabilitation Act), the Individuals with Disabilities Education Act (IDEA), the Higher Education Act of 1965, as amended (HEA), and the Elementary and Secondary Education Act of 1965, as amended (ESEA), by removing the words "mental retardation" and replacing them with the words "intellectual disability" or "intellectual disabilities." We are therefore revising applicable sections in title 34 of the Code of Federal Regulations (CFR)." (Federal Register, 2017)*

"The future of special education will need to focus upon greater inclusion of special education students in our communities in general."

The Workforce Innovation Opportunity Act (WIOA) (H.R. 803) has been hailed as the "most significant piece of legislation for people with disabilities since the passage of the Americans with Disabilities Act of 1990." The focus is on transition-aged youth, which is now defined as ages 14-24 years of age. The Act allocates 15% of State VR budgets to this population. The goal for transition-aged youth is to obtain competitive integrated employment. No more sheltered workshop placements will be allowed. No more sub-minimum wage jobs where individuals with disabilities are exploited. No more closing a case after 90 days. The emphasis is now on longevity in a career and the generation of a living wage. WIOA now allows state offices of Vocational Rehabilitative Services to fund PRE-EMPLOYMENT skills development, including travel training, interview skills, financial literacy, independent living skills, job exploration counseling and even enrollment in a Comprehensive Transition and Post-secondary program.

The Post-9/11 Veterans Educational Assistance Improvements Act of 2008 (P.L. 110-252) and the Post 9/11 Veterans Educational Assistance Improvements Act of 2010 (P.L. 111-377) are not special education laws per se (and are known collectively as the "New G.I. Bill" and the "New G.I. Bill 2.0"). However, they provide an interesting opportunity for the parents of special needs young adults who would like to attend a college-based transition program or CTP. Under these two acts, retired or active-duty military personnel may transfer any of their unused educational benefits to their dependents in order for the dependent to complete their education. This can include vocational training at a college-based transition program. As part of the Acts, the Yellow Ribbon Program was created to offset the higher costs of private colleges and universities. The Yellow Ribbon Program pays the difference between the cost of an education at the retired military personnel's home state's public university and the private university the dependent has chosen to attend. The Acts also pay for books, transportation, room and board, and other expenses.

THE FUTURE

The future of special education, or the next 50 years, will need to focus upon greater inclusion of special education students, not only in higher education, but in our communities in general. Ensuring that our children can read, write, and do basic arithmetic is no longer a sufficient end goal of public education. Special needs students will need to learn independent living and job skills. These goals must be achieved using measurable outcomes. Special education students will need to learn how to be meaningfully engaged and included in their communities. They will need to earn industry-recognized certificates that lead to living wages. The public-school system cannot do this alone. This must be done by creating partnerships between schools, employers, social service agencies, government agencies, houses of worship, and colleges and universities, in order to achieve full inclusion of special education students. No single system can achieve this complex task. It will require a network of individuals and organizations working together to achieve this vision. This vision is within our reach within the next 50 years. •

******A Brief History of Special Education: Milestones in the First 50 Years (Part I) was published in* EP Magazine*'s June 2021 issue.*

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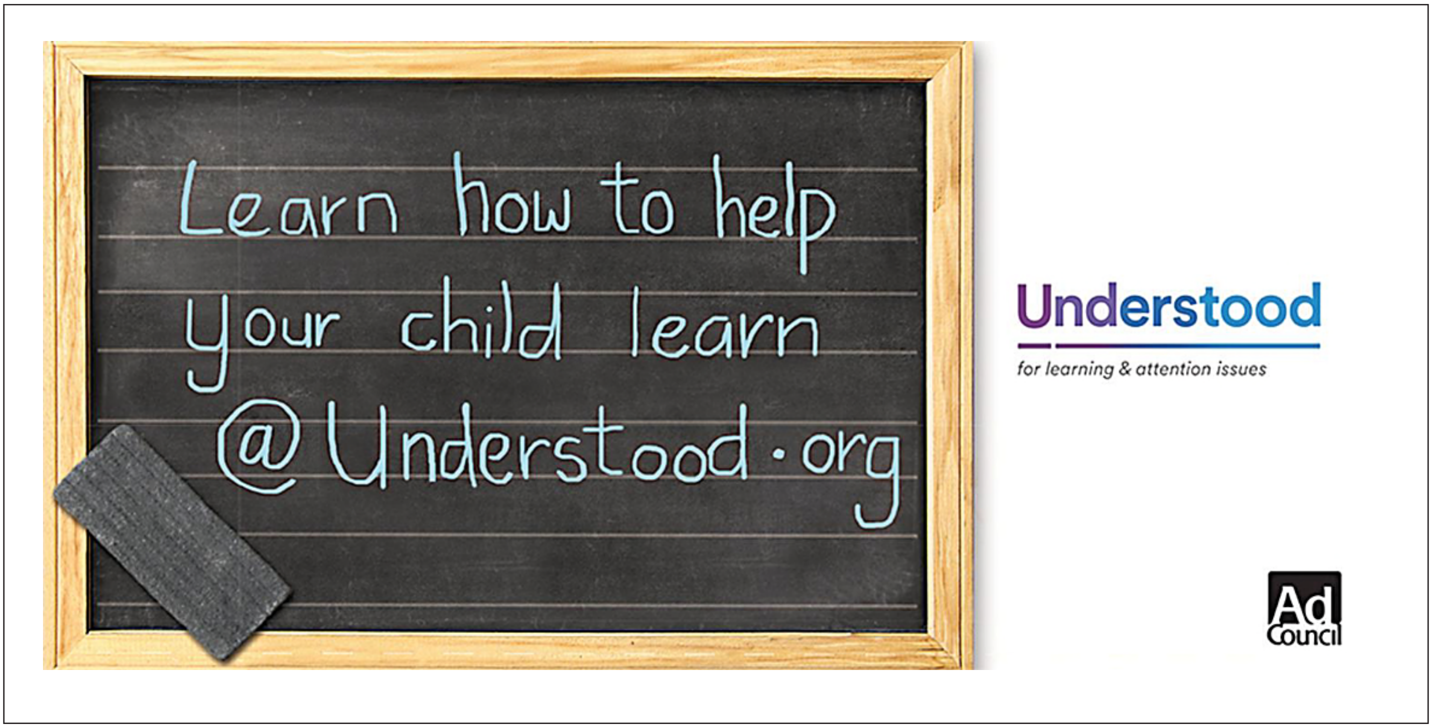

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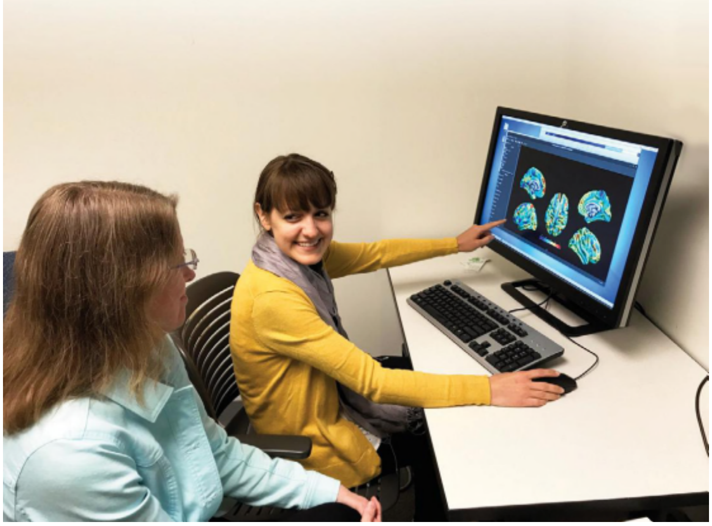

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ADUHELM: RUSH TO JUDGEMENT?

BY THE NTG ADUHELM AND DOWN SYNDROME MEDICAL ADVISORY GROUP

SUMMARY

The authors raise issues related to Down syndrome and the use of Aduhelm, Biogen's new drug for use with early-stage Alzheimer's disease. Issues noted include a lack of data on applicability of drug with adults with Down syndrome, lack of protocols for its use by practitioners, and unknowns as to efficacy of the drug with presence of high amyloid load from early age. Authors recommend (a) including participants with Down syndrome in ongoing and further clinical trials and research, (b) assuring research-informed appropriate oversight over its usage, (c) developing protocols that guide assessment and decision-making for the use of the drug with this group, (d) screening systematically for early symptoms of AD, (e) determining optimal age for prophylactic use of drug, (f) involving families and caregivers in the prescribing and using decision-making process, and (g) providing orientation and education to healthcare providers and ancillary staff involved with use and aftercare.

Globally, people are living longer than ever before, including adults with intellectual disability. Age-associated physical and cognitive decline is commonly a part of the aging process that will eventually have an impact on most people. Some of these changes may be normal but some may herald the onset of dementia stemming from Alzheimer's disease (AD) and other neurodegenerative diseases. As noted by the WHO[1] and in the US National Plan to Address Alzheimer's Disease[2] many adults with an intellectual disability will face the same concerns about cognitive decline when they age and for the most part experience similar prevalence rates of dementia as the general population.[3] However, adults with Down syndrome, one of the most common forms of intellectual disability, have an extremely high risk for AD dementia. Therefore, they face a more substantial concern for developing cognitive decline due to the accumulation of beta amyloid protein, often starting while they are in their teens.[4, 5] As noted by the NIH, DS is a noted risk factor for early-onset AD.[6]

It is estimated that the lifetime risk of AD dementia is >90%[7] and it is the leading cause of death for older adults with Down syndrome.[8] Estimates are that there may be some 57,700 adults age 40 and older with Down syndrome,[9, 10] and that their average age at death is 55.8.[11] Many people with Down syndrome are diagnosed with AD dementia in their 50s but it is not uncommon for symptoms to also occur in their late 40s.[12] Once identified, AD in many people with Down syndrome can be rapid, leading to progressive cognitive decline, and is often associated with significant behavioral distress, seizures, gait dysfunction, markedly increased care needs, and death within five to seven years from diagnosis.[13]

Parents, siblings, and other caregivers embrace, encourage, advocate, and often begin the fight for services and aid for their family members with Down syndrome beginning at birth. This continues throughout childhood, adolescence, and into young adulthood as family members work to ensure their offspring receive access to equitable care and support in all aspects of their lives – including education, healthcare, vocational support, social inclusion, and civil rights. The concern that they will have to deal with and worry about early-onset AD is a hugely emotional and difficult prospect – especially when the previous ensuing years often involved battles to provide a positive and proactive approach to life, the promotion of greater autonomy, and inclusion, and support for the most of what societal integration would offer.

The realization that AD may be on the horizon for many adults with Down syndrome may not have been something that families and other caregivers thought about during earlier years when they were advocating for issues noted above. However, recent research in AD biomarkers and therapeutics for the general population and specifically for adults with Down syndrome has increased attention and dedicated focus to determine whether there might be ameliorative measures forthcoming that might help stave off or mitigate the effects of AD in adults with Down syndrome.[14,15] The recent news of the FDA's accelerated approval of Biogen's Aduhelm (aducanumab)[16] for the treatment of adults with mild cognitive impairment and dementia stemming from AD has created an avalanche of obvious interest about this product's utility and application for adults with Down syndrome.

But is this exciting news justified and does it provide the options and hope that many families have been expecting? The reality is that this new medication's availability is far from a straightforward solution for not only those adults with AD in the general population, but also for adults with Down syndrome and their families.[17]

The conundrum for families, caregivers, and adults with Down syndrome themselves, is this: the clinical trials noting the efficacy of aducanumab were conducted only on neurotypical adults with symptoms of MCI or dementia. Thus, it is unknown to what degree aducanumab may help people with Down syndrome, as they were not included among the trial participants. Questions arise as to

PROCEED WITH CAUTION: As protocols for the use of aducanumab are implemented, adults with Down syndrome must be provided with equitable care and support once diagnosed with AD.

whether aducanumab's impact on brain amyloid, associated vascular complications, doses used and its titration in neurotypical adults may or may not be similar in adults with Down syndrome. Furthermore, cognitive benefits have yet to be clearly demonstrated with aducanumab as well as whether the MRI-related changes [including amyloid related imaging abnormalities (ARIA)] and other possible side effects (e.g., brain swelling and microhemorrhages) would also would also apply to adults with Down syndrome. To what degree are these factors equally applicable for adults with Down syndrome who are at high risk for early-onset dementia stemming from Alzheimer's disease? Are there additional side effects that we may not be aware of as there are no studies that include people with Down syndrome related to the overexpression of other proteins from chromosome 21?

Research in the last several years is providing new data that are beginning to shed evidence about the pathology and natural history of AD in people with Down syndrome, including biomarker research and potential therapeutics.[18, 19] Research demonstrates that beta amyloid (which is present in excess in people with Down syndrome due to the extra copy of the amyloid precursor protein on chromosome 21) begins to accumulate early in life, and steadily builds up over decades long before cognitive decline is notable. [20] The data also indicate AD biomarkers in people with Down syndrome behave similarly to those with other genetic forms of AD.[21] Further, vascular (blood vessel) complications including microhemorrhages (small bleeds) are not uncommon.[22] Like most people who are diagnosed with AD, there are variabilities as to the age of onset of mild cognitive impairment (MCI) and dementia, as well as the rate of progression and its trajectory in people with Down syndrome.

A key question is whether the much earlier accumulation of amyloid and degree of vascular changes that we typically see in older adults with Down syndrome respond to aducanumab in a predictable and clear fashion. Also, as amyloid accumulation is seen in 100% of adults with Down syndrome over age 40, to what degree will this affect testing and assessment for AD, as it is known that this build-up is prevalent also in asymptomatic adults with Down syndrome. During the treatment phase, will the individual's underlying cognitive and lifelong intellectual disability have an impact upon his or her ability to tolerate post-infusion testing (including MRIs) and being exposed to invasive biomarker measures. Given significant loss of cognition in some people with DS and AD (that is not regained) after the often-required anesthesia for MRI, will potential gains from using aducanumab be lost by post-anesthesia effects? Also, will follow-up assessments of their cognition and behaviors be clear to those who must care and support them as well as to provide feedback to the healthcare provider treating them? In addition, what will be the prescribed optimal timeline for receiving infusions and how will decisions be made relative to termination of treatment?

Most healthcare providers, including neurologists, are not trained to assess and diagnose AD in adults with intellectual disability (including adults with Down syndrome). During the pre-prescription assessment phase, specific challenges may arise in communicating with the patient, parsing memory loss from premorbid intellectual functioning, and mitigating examination intolerance. Most memory centers are bereft of staff skilled in interviewing and assessing persons with pre-existing cognitive limitations and who also may be uninformed as to the best courses of health and social care for adults with Down syndrome.[23, 24]

As protocols for the use of aducanumab are implemented, adults with Down syndrome must be provided with equitable care and support once diagnosed with AD. This includes understanding whether prescribing aducanumab is medically indicated and appropriate, as well as ensuring equitable access to the medication once that determination is made (including medication cost supported by insurers and CMS).[25]

Leaders in the Down syndrome advocacy community are exercising due caution at this point with respect to recommendations given the paucity of empirical support for applicability of aducanumab for persons with Down syndrome and are (a) calling for the inclusion of participants with Down syndrome in ongoing and further clinical trials and research, (b) asking for research-informed appropriate oversight over its usage, as well as safety data on aducanumab, and (c) stating that the development of protocols to guide the clinical practice of assessment and decision-making should include provisions for the use of aducanumab with this group. The NIH-funded Alzheimer's Clinical Trials Consortium – Down Syndrome (ACTC-DS) network is poised to address some of these questions in collaboration with Biogen and various regulatory agencies by running safety studies on persons with Down syndrome. However, given the longitudinal nature of such studies, answers to many of these questions may not be available for several years.

Advance protocols for assessment and use should be agreed upon by expert panels to, at minimum, provide cautioned guidance for practitioners considering prescribing aducanumab in adults with Down syndrome (and other intellectual disabilities). Firstly, a well-defined screening process is needed for determining the stage of AD, as well as a well-recognized and approved process for the therapeutic use of aducanumab that all healthcare providers could follow to ensure safety and ability to determine efficacy in adults with Down syndrome specifically, and with adults with intellectual disability generally. Secondly, needed also is a commitment to early detection and screening by the nation's disability services provider network and state regulatory authorities to pick up on early symptoms at a stage when the use of aducanumab may be effective. Thirdly, the involvement of families of the adult with Down syndrome and other caregivers in the decision-making process is imperative and needs to be appreciated while the prescribed medical care is being provided. Lastly, an orientation and education package is necessary to help educate healthcare providers and any ancillary staff involved in the clinical use of this therapeutic.

The strong and cohesive network of Down syndrome advocacy stakeholders and associated professional and healthcare groups are willing and able to work in partnership with governmental agencies and provider associations, as well as with the biopharmaceutical industry to move this forward. We all wish for the new advancements in AD therapeutics to succeed for the millions affected by sporadic AD as well as those thousands who are genetically determined to develop early-onset AD. Dedicated clinical trials for people with Down syndrome or the inclusion of people with Down syndrome in ongoing studies is critical. Building an information base to aid with the assessment of AD dementia in adults with Down syndrome, providing medical management guidelines when therapeutics are prescribed and used, and follow-along guidance not only for recognizing adverse effects, but also for enabling those adults on the medication to function optimally with clinically meaningful benefit.

Thus, we are calling for action. •

This article, the result of a collaborative effort, was coordinated by the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) and led by Seth M. Keller, MD, Co-President of the NTG.

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PART II: EP MAGAZINE SLEEP SERIES

HOW DO WE SLEEP?

BY OLIVIA VEATCH, PHD

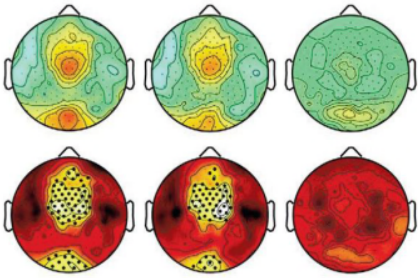
In the first article in this sleep series, we learned about different theories to explain why we sleep. Most notably, while we still don't know for sure all of the reasons we sleep, we know that a good night's sleep is vital for staying healthy. Furthermore, being awake at times when the brain and body are sending signals to go to sleep, or the other way around, can be harmful to our health.

While we all have differences that make us unique, the need to sleep is something that all humans share with each other as well as with most other species on Earth. In this article, I will offer insight into the biology that connects us to our environment by guiding how we fall asleep and wake up using cues from the sun and our planet. It is important to point out that how we sleep changes as we grow. Newborn babies usually sleep a lot throughout the day but are awake at night. This is likely because something called circadian rhythms are not fully formed yet. Circadian rhythms are changes in our bodies, minds, and behaviors that follow a cycle which is very close to 24-hours. Circadian rhythms are

AN EP SPECIAL SLEEP SERIES
PART II

so important that they are one of the earliest biological systems that emerges in babies. These rhythms usually develop by the time babies reach two to three months of age. Once important physical changes in an infant's body begin to follow a 24-hour cycle more closely, they begin to sleep more regularly during the night. They also sleep for less time over a 24-hour period. As children age, they usually take fewer naps and eventually settle into a pattern where they stay awake during the day and sleep throughout the night.

Circadian rhythms occur in almost every cell and tissue of our bodies. These rhythms are governed by our genes and allow us to time when we are awake and asleep in response to sunlight and darkness. More precisely, there is a set of genes, called "clock genes," that turn on and off over the course of the day and night. Once these genes are turned on, or expressed, they produce proteins and a cascade of internal events occurs that affects our entire beings. These events not only include putting us to sleep but also producing hormones and regulating our metabolisms. To allow these events to be cyclic, some clock genes make proteins that work to express other clock genes. These, in turn, make proteins that build up in our systems over the day and eventually can turn off their own genes. Then the cycle of switching clock genes on and off begins again. This biological clock can keep time even in the absence of sunlight. Importantly, even though biological clocks continue to run without light and dark changes, when our eyes see sunlight, wake-promoting clock genes can turn on rapidly. Therefore, it is important to align our sleeping, eating, and exercising to coincide with the cues we receive from our environment.



> "The genetic changes that contribute to a child having a developmental or intellectual disability can also cause our brains to signal for us to sleep at the wrong time."

Similar to many of the important processes that our bodies perform, there are checks and balances that help control sleeping and waking periods. For instance, our biological clocks are helped by another process called sleep/wake homeostasis. Basically, this means that the longer we stay awake, the more our bodies realize the need to put us back to sleep. Also, just like our clock genes, many other signals that help wake us up or put us to sleep are sent by our bodies in response to signals we receive from our environment. Namely, when we see sunlight, a signal is sent to our brains that tells us to stop making something called melatonin. Melatonin works to help us go to sleep by sending sleep-promoting signals from the brain to different parts of the body. Since these sleep-promoting signals stop being sent in response to sunlight, this helps explain why looking at devices that emit artificial light can make it harder to fall asleep at night. Some wavelengths of artificial light, like the sun, can send signals to our brains that stop us from making melatonin. Once we stop producing melatonin, it can no longer work to help us fall asleep. It also can't perform its other important duties which include fighting infections and promoting immunity.

Melatonin is produced from serotonin by a series of chemical reactions. Serotonin is important for helping us control our moods and stay focused. Light exposure, especially early in the morning, may help increase the amount of serotonin in our brains. This can then allow for more melatonin to be made when the sun begins to set. This is why people think that experiencing bright light early in the morning can help us fall asleep more easily at night. Exposure to light also stimulates adrenaline and cortisol production. Both of these hormones impact our ability to convert food into energy. They also influence how we respond to different types of stress. Circadian rhythms are not only influenced by light but also by temperature and seasonal changes. Because many processes in our bodies are closely regulated by circadian rhythms, timing is indeed everything. The time of day when we expose our eyes to light, eat and exercise can all influence how we sleep and how well our metabolisms work. In the end, circadian rhythms evolved so that we could live healthier and more comfortably in our earthly environment.

Sometimes, however, the genetic changes that make us unique can change how our bodies respond to the cues we receive from the environment. For example, the genetic changes that contribute to a child having a developmental or intellectual disability can also cause our brains to signal for us to sleep at the wrong time. A well-described illustration of this is for people who have Smith-Magenis syndrome. Individuals with this syndrome produce the most amounts of melatonin early in the morning instead of at night. This happens because a gene located in the part of the chromosome that is deleted in individuals with Smith-Magenis syndrome also provides instructions for making a protein that helps turn on and off several genes involved in circadian rhythms. Researchers are finding that changes in many genes that aren't known to cause other conditions could also alter our circadian rhythms. We are still learning what all of these changes are and how they work. But as we continue finding the links joining the changes in our genes with the changes in when people sleep, we are learning how to better treat these problems. However, even without special medical treatments, when we understand at what time our own personal clocks are set, then we can better identify ways to use this information for improving our health.

It also valuable to note that – just like circadian rhythms – the physiology of sleep, or how our brain moves through different sleep stages, also changes as we grow from infants into children. Sleep physiology continues to change as we grow into adolescents and adults. In fact, sleep patterns even change as we age from middle-age into our elderly years. But before explaining how sleep patterns change as our bodies change, it may be useful to define the stages of sleep.

Sleep can be broken up into four stages that are defined by measuring brain waves using electrodes. The stages of sleep include light sleep (N1 or Stage 1), moderately deep sleep (N2 or Stage 2), very deep sleep (N3 or Stage 3) and dream sleep (REM or rapid eye movement sleep stage). While sleep is staged using devices that capture brain waves, different sleep stages also have physical characteristics that can be observed simply by looking at someone who is sleeping. Light sleep can be recognized when someone's breathing slows to a regular pace. The second stage of sleep can be recognized when someone's heart rate slows down, and their body temperature drops. In the deepest stage of sleep, our bodies reach a point of extreme relaxation. This is why it is very difficult to wake someone up when they are in Stage 3 sleep. These first three stages are collectively called non-REM sleep. REM sleep can be recognized when someone's breathing is not regular, and their eyes are quickly moving under their lids. Our bodies also try their best to keep our muscles paralyzed during this stage of sleep, so we don't act out our dreams. There are many theories about what happens in our brains and bodies during different stages of sleep. It is thought that each stage of sleep may allow for many of the reasons why we sleep to occur – like those presented in the previous article in this sleep series. It is also possible that different parts of our brains do different things during different stages of sleep. Even though we may not know all of the reasons for the different sleep stages, it is becoming clear that each stage of sleep serves a purpose for ultimately renewing our minds and bodies.

"Researchers have found that sleep problems relate to worse daytime symptoms in children with ASD. Treating these sleep problems can improve daytime symptoms."

Now that sleep physiology has been defined, the way these patterns change throughout a person's life can be more easily described. Once someone's circadian rhythm starts to settle into a regular pattern, sleep stages tend to do the same. Usually, we move from being awake into the first phase of light sleep. Light sleep tends to last for only a short period of time, generally just a few minutes. Soon our sleep becomes deeper and we move into the second stage of sleep. This stage of sleep lasts much longer than the first stage. We then move from the second sleep stage into our deepest sleep. After we spend some time in the third stage of sleep, we begin dreaming. Our brains then repeat the cycle of moving through each stage of sleep. As we move through more and more complete cycles during the night, we spend less time in our deepest stage of sleep. Instead of deep sleep, we spend time dreaming and sometimes our brains can move from Stage 2 sleep straight into the dreaming stage. Newborn babies may sleep as much as 18 hours during a single 24-hour period, and they spend almost half of that time in REM sleep. They may also not move through every stage of sleep but instead go from being awake directly into the dreaming stage.

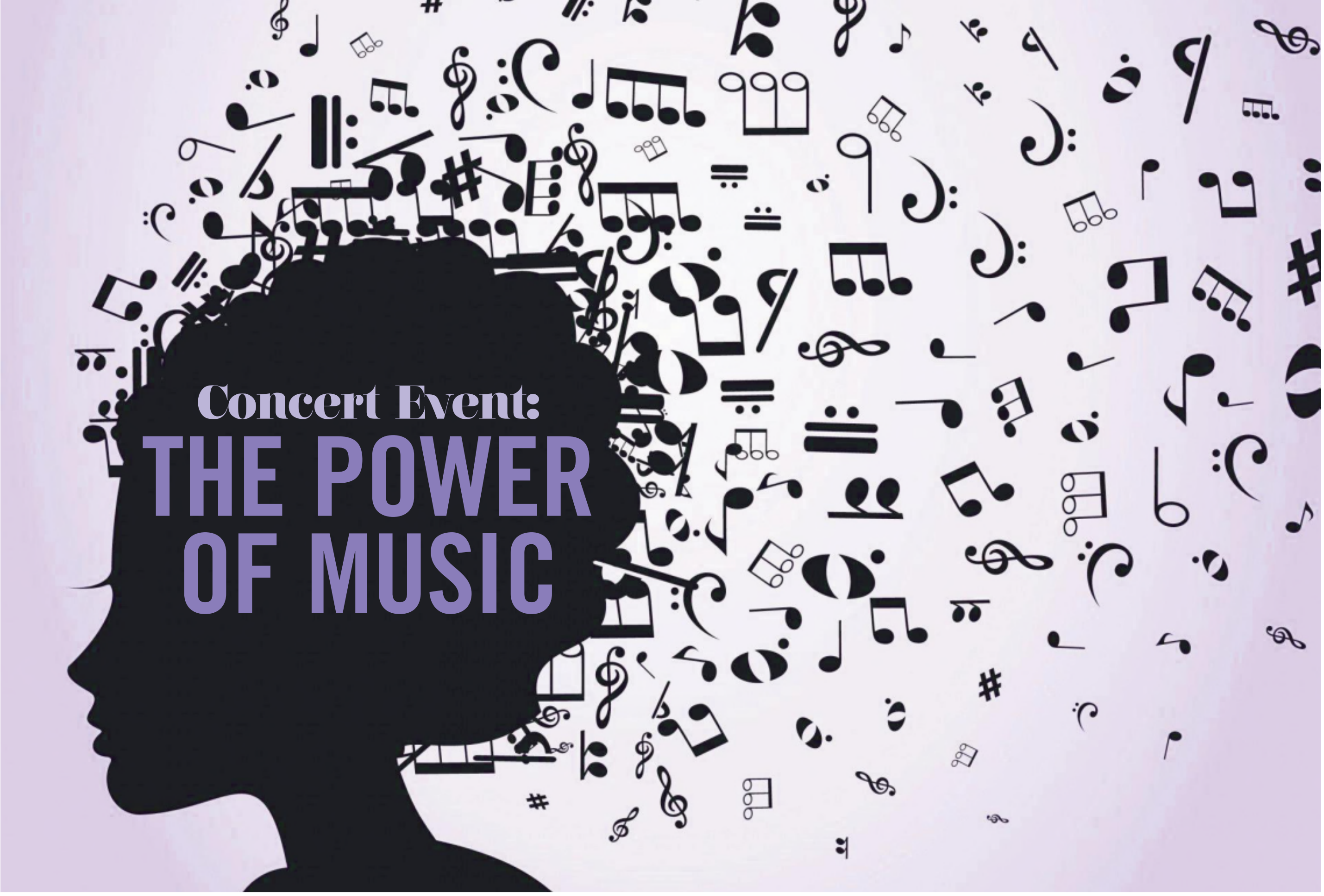
As people get older, they begin to sleep for less time during a 24-hour period. Most adults need only seven to eight hours of good quality sleep to feel rested in the morning. Adults also spend less of their sleep time in the deepest stage of sleep and more in the second stage of sleep. Research has also shown that changes in our genetic material can also alter our sleep stages. For example, genetic changes have been found to relate to sleep problems like narcolepsy and insomnia. We are still learning about how our genes can change sleep physiology, why sleep changes as we age and grow, and how each stage of sleep is important to our overall well-being.

Even though we may not understand why all of these biological phenomena occur, knowing how circadian rhythms and sleep patterns typically develop across the lifespan allows us to notice when these are atypical. This is especially interesting since these biological systems are established months, and sometimes years before many developmental or intellectual conditions can be diagnosed. It is possible that atypical patterns of circadian rhythms and sleep patterns are indicative of a child having a developmental or intellectual disability that could benefit from earlier interventions. One intervention may be to focus directly on finding better ways to improve sleep behaviors. For example, researchers have found that sleep problems relate to worse daytime symptoms in children with autism spectrum disorder (ASD). Furthermore, treating these sleep problems can improve daytime symptoms. Symptoms of ASD could give rise to sleep problems. It's also possible that the same genes affect both ASD symptoms and sleep problems. In fact, some of the genes involved in the development of our brains play the same roles in biology as genes that affect sleep physiology and the timing of sleep and wake. This is also true for our metabolisms. This suggests that the biology of sleep, neurodevelopment and metabolism could be connected. For those of us who research these connections, the hope is that this work will help us find better ways to treat sleep and circadian rhythm problems.

To summarize, although we know a considerable amount about the biology of how we sleep, there is still a lot to learn. The more we learn, the easier it will be to help people get better quality sleep. It's possible that finding ways to get proper sleep during the early years of life has positive health impacts that extend into adulthood. Ultimately, finding ways to get better sleep at the right time should allow us to fully benefit from our biological connection with the natural world.•

ABOUT THE AUTHOR:

Dr. Olivia Veatch is an assistant professor in the department of Psychiatry and Behavioral Sciences at the University of Kansas Medical Center. She has a Ph.D. in Human Genetics. Dr. Veatch's research focuses on combining evidence from the laboratory with the power of computers to find ways that genetics can help inform healthcare. She is particularly interested in understanding the genetic changes that contribute to sleep problems in individuals with developmental or intellectual conditions.



Concert Event:

THE POWER OF MUSIC

BY MARTHA SUMMA-CHADWICK, DMA

Music is essential to human experience, but most people are generally unaware of recent advances in science-based music therapy practices. To help disseminate this knowledge, the Chattanooga-based nonprofit organization Music Therapy Gateway in Communications (MTGIC) created an annual concert series beginning in 2013 that, while it entertains, has educated its audiences regarding the positive therapeutic outcomes of music.

Previous concerts featured works by composers who overcame neural challenges, as well as upbeat contemporary music to help the audience experience how easily and subconsciously their muscles move to rhythm. These yearly events have been designed to bridge the perceived gap between the aesthetic and therapeutic benefits of music, and to advocate for the remarkable potential that music protocols could produce in mainstream medicine.

Due to the COVID-19 pandemic, this year's concert event was available entirely in a virtual format. The Power of Music concert, supported by a grant from the Tennessee Arts Commission, premiered on June 1, 2021, on the YouTube platform. The full concert remained available for viewing for an additional 30 days following the premiere. Additional components of the Power of Music event included a pre-concert symposium featuring a stellar panel of experts discussing various elements of music in science and education, and spoken tributes discussing the importance of music to the individual and the community. The event website, www.powerofmusicconcert.com, remains active and contains links to concert highlights, preconcert webinar, and spoken tributes, as well as program notes, participant bios and pictures, and a general overview of the power of music when utilized aesthetically and therapeutically. As of July 1, 2021, audiences can still access the violin/piano selections, the pre-concert webinar, and the spoken tributes from the website; these videos will remain online indefinitely, with links remaining accessible from the event website.

MTGIC partnered with the University of Tennessee at Chattanooga (UTC) Department of Performing Arts for this event; UTC graciously donated their facilities and recording team for all video segments. The concert performance, which was recorded live at Cadek Hall on the UTC campus in early April 2021, featured Richard Cox, tenor; Mark Reneau, violin; and Dr. Martha Summa-Chadwick, pianist and MTGIC Executive Director. Program selections represented many different genres and styles,[1] reflecting the diversity of music that provided comfort to people during the pandemic. Included were comedic and sentimental songs by American songwriter Stephen Foster and beautifully stylized art songs for voice and piano by Richard Strauss. Maurice Ravel was inspired by American jazz; the second movement of his violin sonata shows a strong blues influence in the unique compositional development of this work. Operatic selections were also represented, as well as movements from Manuel de Falla's Suite Populaire Espagnole, arranged for violin and piano. The concert concluded with a delightful array of Tin-

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[1] Due to licensing inconsistencies for virtual performances, all music selected for programming in this concert is available in the public domain.

PHOTO PROVIDED BY MARTHA SUMMA-CHADWICK, DMA

POWER PLAY: Concert performers included *(left to right)* Martha Summa-Chadwick, piano, Richard Cox, tenor, Mark Reneau, violin.

Pan Alley songs representing Broadway, stage, and screen. These charming pieces demonstrated how music influences muscle movement by encouraging the audience to notice how they automatically tap a finger or toe to keep time with the music.

The expert panel participating in the pre-concert educational webinar represented the professions of health care, music, and education. Panel members were Dr. Stuart Benkert, Department Head of UTC's Department of Performing Arts; Bob Bernhardt, Music Director Emeritus and Principal Pops Conductor of the Chattanooga Symphony and Opera; Dr. Rick Rader, Director of the Morton J. Kent Habilitation Center at Chattanooga's Orange Grove Center and Editor in Chief of *EP Magazine*; and Dr. Martha Summa-Chadwick, MTGIC Executive Director. The group discussion incorporated in-depth dialogue regarding the power of music from a range of diverse viewpoints, with conversation regarding science, therapy, education, enrichment, inclusion and community. Additional videos featuring former Tennessee Senator Lamar Alexander, and Stratton Tingle, Executive Director of Chattanooga's SoundCorps organization, were also included to pay tribute to the power of music for the individual and in the community by demonstrating the impact of music on society.

MUSIC TO OUR EARS : ADDITIONAL RESOURCES

For more information regarding the Power of Music concert event, additional information about the performers and speakers, or a more in-depth view of the benefits of biomedical music protocols, please visit the following websites:

POWER OF MUSIC
www.powerofmusicconcert.com

MTGIC
www.mtgic.org

SOUNDCORPS OF CHATTANOOGA
www.soundcorps.org

RICHARD COX
www.richardcoxtenor.com

MARTHA SUMMA-CHADWICK
www.marthasumma.com

Research studies suggest that a large majority of people have reached out to music as a primary source for comfort and entertainment during the worldwide pandemic. Music is a vital universal language that enhances emotional experiences, communication, and physical movement. In addition to the well-known aesthetic benefits of music, science confirms that it is a direct channel to the brain. The use of music protocols in medicine could significantly benefit people with motor, speech, and cognition challenges resulting from such conditions as autism, stroke, cerebral palsy, Parkinson's disease, and many other diagnoses. A remarkable body of excellent research verifying the benefits of music therapy is available in scientific journals, but this knowledge is generally unknown to most people, who typically attend a concert for the pure joy of listening to the music. The Power of Music event sought to present an overview of the potential of music in therapy, while also providing a delightful musical experience for the audience. •

ABOUT THE AUTHOR:

Martha Summa-Chadwick has achieved a national reputation as an educator, presenter, performer, and advocate for the cause of music in therapy. She has performed as piano and harpsichord soloist with orchestras across the country and served for twenty-six years on the faculty of the Cadek Conservatory of the University of Tennessee at Chattanooga, Tennessee. For the past decade, Dr. Summa-Chadwick has explored various ways to use music for therapeutic as well as aesthetic ends. She is the Executive Director of the nonprofit organization Music Therapy Gateway in Communications, Inc., and a frequent guest speaker at both national and regional conferences, discussing the use of biomedical music techniques for challenged children. She has given two TED talks, and is also exploring how biomedical music protocols could be automated into software applications for persons with motor, speech, or cognition challenges.

Hope for Families Through

Jack's Basket

BY CARISSA CARROLL, M.ED

Eight years ago, I sat in in a hospital bed, just having given birth to my second son, Jack, by emergency c-section. Little did I know that the unexpected turn of events of how his delivery went would pale in comparison to the unexpected news that would come shortly after, changing our lives forever. His birth diagnosis of Down syndrome was given in such an abrupt and insensitive way by the nurse practitioner, while my husband waited alone while I was in recovery.

"Are you aware of Trisomy 21? Your baby is showing signs of Down syndrome." She continued with, "Well, just enjoy your baby," and then left the room. My husband was left with our newborn, not knowing how this would impact our future, and the responsibility to share the news with his wife. Holding emotions of confusion, shock, and fear, our journey began.

* * *

Navigating those first months, the grief and tears came because I was holding onto the real and raw feelings that having a child with Down syndrome was not a part of my plan. As a goal-oriented person, I certainly wasn't prepared to slow down my pace with special needs, additional appointments, therapies, and all that comes with the journey of Down syndrome.

REASON TO CELEBRATE: Jack's Basket, inspired by Jack Carroll, has a vision that every baby uniquely created with Down syndrome would be welcomed, their family congratulated and connected to the supportive community, and provided the resources that are

Those tears also came because of the fear of how it would change us. Slowly, I accepted that I wasn't in control, which led me to surrender my plans. This opened my eyes to a whole new perspective, allowing me to truly accept Jack for who he is, embracing every part of him and this journey, which has produced a love and life I wish everyone could know.

As we approached his first birthday, my college classmate had reached out, asking if I would meet up with her friend who had found herself on the same unexpected journey we were on with Jack. I could see the grief in her eyes and how she talked about her daughter.

I asked the first-time mom, "How did you hear the news of your daughter's diagnosis?" She explained that seconds after giving birth, a nurse yelled, "This baby has Down syndrome, get her to the NICU immediately!" I continued with questions about her health at birth and she reflected that the only reason for the traumatic announcement being shouted out in the room before seeing or holding her baby was because she was showing signs of the diagnosis. My heart grieved with hers as she recalled that moment and led me to assume that is why I could still see the deep grief, seven months later.

"How was your stay in the hospital?" She continued to share that the three weeks they were in the hospital working on feeding, no one congratulated them on the birth of their daughter.

"We were treated like we had the plague." My heart broke for her and her child. They deserved better.

I couldn't stop thinking about her experience and how she heard the news. I believed how it was told and their experience was making a direct impact on her ability to accept her new life with her daughter. Yet, her story was like so many I had heard in that first year of Jack's life and it was igniting a fire in my heart that desired for these stories to be different.

Every child deserves to be celebrated, every family should hear a "congratulations" instead of "I'm sorry," or "I have bad news." The personal bias of the provider should not be the start of the story. So, I decided to do something about it.

On March 25th, 2014, Jack's first birthday, we went back to the hospital and brought a gift basket filled with newborn gifts welcoming a baby worth of celebration. The basket was also filled with local and national resources, in celebration of a new baby diagnosed with Down syndrome. A letter from our family to theirs, expressing what Jack's life had taught us in that first year. A community ready with open arms, to share that life is filled with unexpected joy, and their child would change them for the better.

So many families were leaving hospitals without any information and access to the free programs and resources available to families. A few weeks later, we found out a family received the basket and it brought the family hope for the future. The mom shared it was the only congratulations they received during their stay in the hospital. That broke my heart, again. I was determined to change that for future families by going to the start of the story. That was the birth of Jack's Basket.

Often times, I am asked, what would I have liked to have heard. "I have unexpected news." Those are the words I wish we would have heard after the congratulations, while together, when the nurse practitioner shared

Jack's diagnosis. Four simple words that don't carry any assumptions, biases, or pity. I had a desire to empower providers with tools in how to share the news, based on families' experiences and help them understand the role they have in the start of the story. Equipping them with words and a helpful resource to support their patients on new unexpected journey.

jacksbasket

jacksbasket Over the course of nine weeks, my mom was asked seven times by different medical providers if she wanted to end her pregnancy because they discovered I have Down syndrome. I am now six months old and have been impacting lives for the better. Don't make assumptions about my life. It has great worth. Love and respect me. Accept me for who I am. ✨

Baby I, you deserved better and so did your family. You are worthy of celebration because you are...you. 🎁

We see you, accept you, believe in you, and celebrate you. Because of how your story started, we will be strong and courageous, and continue to work hard for you and others, so that the world can speak life, not fear. 🤍

Jack's Basket exists to eliminate bias. Join us on this mission of celebrating babies with Down syndrome and our work to educate and empower providers, giving them tools to deliver the diagnosis in an unbiased way. ✨

Since 2014, we've been honored to welcome and celebrate over 4,000 babies around the world in 29 countries and 50 states. We've presented to thousands of providers across the United States, including Grand Rounds at major hospitals, and published a journal publication in Pediatrics in July 2018 titled, When Bad News Isn't Bad, Recognizing Provider Bias When Sharing Unexpected News. We connect with physicians, genetic counselors, and other healthcare providers that care for families at time of diagnosis or shortly after (prenatal and postnatal). You can find more information about our medical outreach at www.jacksbasket.org/medical-providers

Providing hope to new families through Jack's Basket is changing the narrative around the diagnosis. Hope that the future is filled with love, joy, and growth. I never would have imagined that an idea of celebrating Jack's first birthday with a gift basket for another family would ever impact the world the way it has. I am thankful for the call that has been placed on my heart to celebrate these precious babies, encourage and connect parents, and create change in how the diagnosis is given by healthcare providers. I am most thankful for a little boy named Jack that changed my heart in the very best ways.

Jack's love for people is contagious and it's given freely without conditions. He knows exactly the perfect time for a hug. My new favorite thing he tells me (besides "I love you") is, "Mom, calm down. Take a breath." Yes, Jack… thank you, I'll take a breath. When he senses someone's angry or frustrated, he draws in close, places his arm on your back and asks, "You happy?" His simple questions and phrases remind me of what is important. He challenges me to be empathetic, to be near, and to love no matter what.

Because of Jack, I am more patient and accepting. Because of him, I choose to go outside of what's comfortable and easy, to advocate and speak life into a broken world. Jack has encouraged me to look at each person, created with a purpose, with an ability to make the world a better place. My heart wishes that the world would do the same for him.

I would not change Jack for the world, but I will change the world because of him. •

ABOUT JACK'S BASKET

CELEBRATING BABIES WITH DOWN SYNDROME
Jack's
BASKET
ESTABLISHED
· 2014 ·

Jack's Basket is a 501(c)3 nonprofit organization with a mission to celebrate babies with Down syndrome. We strive to ensure that every new and expectant parent is provided resources and avenues of support within the community. We aim to educate medical providers on how to discuss the diagnosis in an unbiased way in hopes that having a baby with Down syndrome is celebrated like any other.

ABOUT THE AUTHORS:

Carissa Carroll, M.Ed., is an alumna of Bethel University and the University of Minnesota. She taught at the elementary and collegiate levels before a sweet baby boy named Jack changed her heart and passion. After an abrupt and assumptive diagnosis experience, Carissa felt led to start Jack's Basket. She wanted to make a change for future parents, ensuring that they felt their child was a reason to celebrate and have opportunities to connect within the community. Carissa presents to medical professionals about how to deliver the diagnosis without bias, works with the Jack's Basket board and community to further the mission, and connects with volunteers who deliver baskets. When not pursuing her passion, Carissa can be found enjoying an early morning long run, quality time with her husband, and soaking up the days with her two sons and daughter. Learn more about Jack's Basket at www.jacksbasket.org

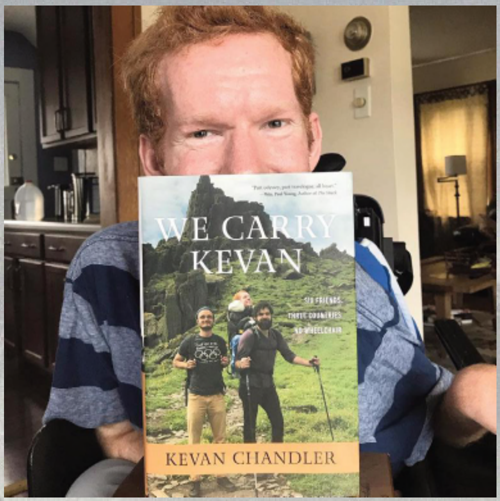
My Adventure with Dad

BY KEVAN CHANDLER

SUMMER TRAVEL • GET UP & GO

I was asked to tell you a story about one of my adventures. About five years ago, some friends and I decided to travel around Europe for three weeks, leaving behind my wheelchair and going to places I couldn't otherwise get to. I have Spinal Muscular Atrophy, which means this was considered by pretty much everyone to be a crazy idea, but those are just the kind of ideas I love the most. So, we made it happen! We did this by creating a specially modified backpack for these friends to carry me around in. We got to dance through the streets of Paris, hop fences in the English countryside, and climb to an ancient monastery at the top of Skellig Michael, off the coast of Ireland. And, most important, we got to do all of this *together.*

From there, doors opened for me to speak around the world about friendship and accessibility, and where those two things intersect. I had the wonderful opportunity to give a TEDTalk in Ireland and had the pleasure of publishing a book about our trip to Europe, entitled *We Carry Kevan.* I've also been honored to start a nonprofit by the same name, with several people who are much more equipped than me to start such things. The nonprofit, and the book and everything else, came from a boon in interest from families with disabilities who saw our adventure take place and began asking questions. Where'd you get this backpack? Where'd you get these friends? How did you guys make this dream come true? So, we set out, and continue, to redefine accessibility as a cooperative effort, which means people helping people.



CARRY THAT WEIGHT: When reading his book, the reader sits with Kevan – one head-level above everyone else – and enjoys a camaraderie unlike any most people ever experience.

And that turned out to be just the beginning. So, a story about one of my adventures… I could tell you about the time we missed our train to London, or when we broke my nose in a car accident outside Dublin; I could recall how a Buddhist monk snuck a photo of us on his iPhone at the Shaolin Temple, or that my friend Tom and I unknowingly swam with a shark once in the Pacific; we could laugh together as I recount the various strange looks my friends and I have gotten over the years, or we could give a collective sigh over the first date my wife and I had, splitting fish 'n chips on the beach in Sydney, Australia. There are countless stories I could tell you. They are all dear to me, and most of them have a point to them, I promise. But this is a magazine that celebrates exceptional parents, and mine are very much that, so let's talk about them. I'm going to tell you a story about one of my adventures with my dad, in particular.

Earlier, I mentioned the Shaolin Temple, which is in China. After our trip to Europe in 2016, the guys and I decided that China was our next big endeavor, and it came together in 2018. The team, this time, was spread across the U.S. and Canada, so we decided to all rendezvous in Vancouver, B.C., and fly out to Shanghai from there. I live in Fort Wayne, Indiana, so my dad and I took advantage of the plan, turning it into a long-overdue father-son road trip. He flew up to Fort Wayne from North Carolina and we hit the road, heading north through the Great Lakes into Ontario, then hung a left, taking the Trans-Canada Highway 1 straight across until we reached the ocean. This ended up being a six-day drive, plus a ferry ride

PHOTOS FROM WECARRYKEVAN.COM

to Victoria to see family.

On our road trip, dad and I saw the brilliant vastness of God's creation. From the countless pockmark islands within Lake of the Woods to the wide-open Badlands and the hulking Rockies, shrouded – at the time – in the smoke of unstoppable forest fires. Who would've thought anything could hide such grandeur? But smoke rolled in, thick as mud, and you'd never even know the legendary mountains were there until you were right up against them. And that's when they suddenly felt less like earthly hills, and more like fairytale giants that might tip our world off its axis if they moved too much. Please don't move too much, dear mountains. Don't sneeze, whatever you do! Finally, we made it to the Pacific Ocean, with waves just as big and stories all its own.

A LITTLE HELP FROM MY FRIENDS: "We Carry Kevan" was the name of the campaign that Kevan and his friends used to raise funds and awareness about their trip to Europe in 2016 and later China in 2018. We Carry Kevan now has a mission to mobilize individuals with disabilities by redefining accessibility as a cooperative effort through investment, interaction, and innovation.

We ate our weight in roadside pasties, my favorite British (Irish?) dish; basically, a Hot Pocket, but far superior in every possible way. We also had Thai food with my cousin Josh in Calgary, right after we slipped into the zoo during closing time. As the masses poured out through the exit tunnels, we wove our way casually against the current to get inside, like we knew exactly what we were doing. After all, we were only in town for the one evening and we had to find the playground there that dad had visited as a young boy. He remembered it so clearly! But I'm sad to say (and consider yourselves warned), the Calgary Zoo has made some updates and changes since my dad was nine years old. Now there's a penguin exhibit where hippo slides and giraffe swing-sets used to be. We took our time wandering around the empty zoo until we started looking suspicious and then strategically found our way out, deftly avoiding security.

And in Victoria, back on the subject of food, we enjoyed—for the first time in my life—calamari, fried within minutes of being caught (jigged?) and eaten right out of the pan, courtesy of my cousin, Glenallen.

As we drove the 2,600-some miles across North America, we talked about girls and cars, churches, and road signs. Dad told me stories about his childhood and growing up with my grandpa, who passed away just two months later. I learned about my parents' sweet friendship before they started dating and how their courtship unfolded. He told me about their early years of marriage, barely making ends meet and living off their love for one another. I've always been so thankful for my parents' marriage and the example they've given my siblings and me of just how good it can be to share your life fully with another and surrender together to Jesus. So, to hear their story told so wholly, and especially from my dad—such a godly man—in this one-fell swoop of a week on the road without distractions, it was a kind of fulfillment for me as a man myself, a game changer in my understanding of life and love.

"To hear my parents' story told so wholly was a kind of fulfillment for me as a man myself, a game changer in my understanding of life and love."

It was truly a special time for both of us and a road trip to remember. There were some difficult things that happened as well. We took wrong turns on the map (yes, we used a real, old-fashioned map) and sometimes, hotel rooms weren't what we'd been promised. All minor problems, but then I got a call that one of our guys on the team wouldn't be able to make it, due to a family emergency. I was on the road, but even if I were home, what could I do to help? Finding a replacement to go to China isn't the same as going to France or England. You need a visa (a very expensive visa), and to get a visa, you have to be invited officially by someone in China and then submit a stack of paperwork and then wait several months for approval. A couple of friends back home, including another one of our team members, took on the project, promising me they'd have it worked out by the time we all met up in Vancouver. So, I could do nothing but simply trust and move forward, and my dad was amazing at helping me do this. He prayed with me and remained present with me.

TICKET TO RIDE: Kevan and his dad preparing to embark for Vancouver in 2018; An avid storyteller, Kevan has authored several books, including a memoir of his adventures with his dedicated friends, and speaks worldwide about his unique life with a disability. He is the the founder of We Carry Kevan, a nonprofit striving to redefine accessibility as a cooperative effort.

Similarly, I wrestled with some profound stomach pain throughout the first few days of our drive, which I can only track back unfortunately to the malaria-prevention medicine I had begun taking. This pain came with discomfort in driving, inability to eat, and loss of sleep, none of which are good for the road. But again, my dad, faithful and kind, remained patient and present as my body did what it had to do to work out the issue.

> "The greatest, most real of all adventures is a drive through the human soul. I encourage everyone to go on that adventure, and I encourage you to not go on it alone."

My dad is a quiet man. He's resourceful, clever, and I've never met a harder worker, but his presence is gentle and reserved. He is the epitome of a deacon in the church. I've joked with friends that he's like Robert Redford, if he played a mix of MacGyver and Jesus in a movie. And pretty much anyone who meets him will agree. But I want to talk more about that ability (dare I say, capacity) to be present, because that's key here.

My dad and I went on an adventure together, a road trip across the continent. It was an adventure, not because of the magnanimous gesture of it, but because of a lot of little moments with even littler decisions. And those moments can only be caught, those decisions only be made, if you're present. My dad was not only present himself, but he fostered the posture so that I could be present with him, and this made for the true adventure, beyond road trips and pasties and forest fires.

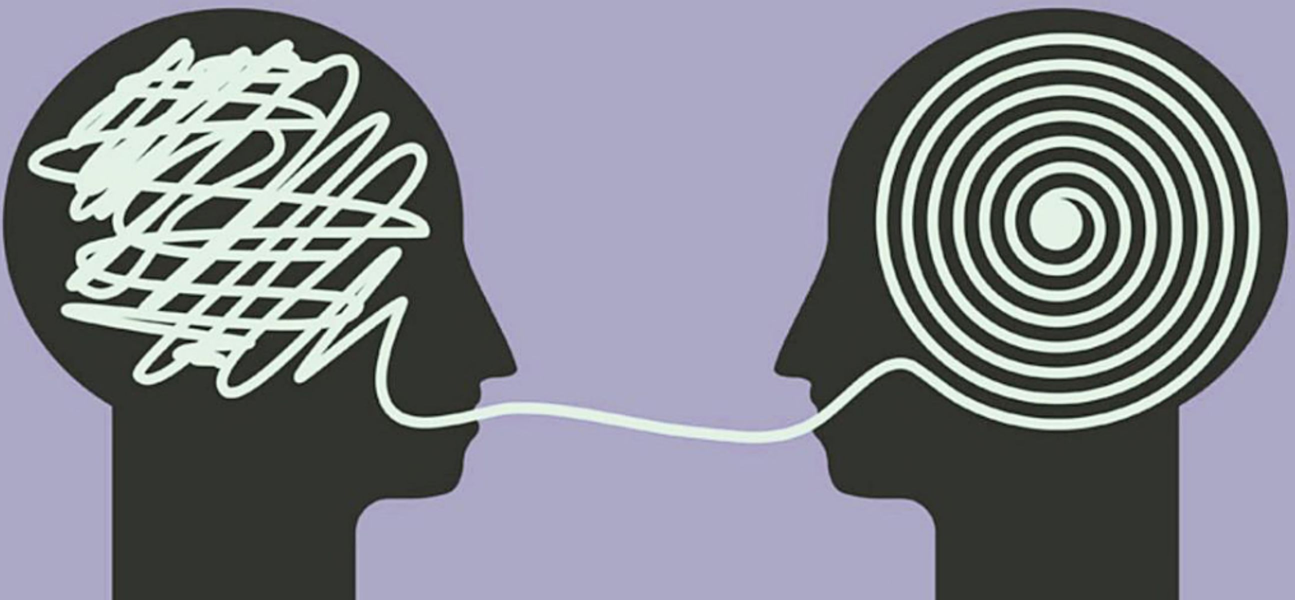
The greatest, most real of all adventures is a drive through the human soul, tasting the fruits of the Spirit, facing down the giants (much bigger than the Rockies) in your own heart. I encourage everyone to go on that adventure, and I encourage you to not go on it alone. Take with you someone who loves you and will be present with you. I had my dad for that adventure, and I have him with me still, which makes life as a whole an adventure. I'm grateful to live it with him, for the stories I can tell from our time together, and the stories yet to come.

ABOUT THE AUTHOR:

Kevan Chandler grew up in the foothills of North Carolina with his parents and two siblings. The youngest of the bunch, he was the second to be diagnosed with spinal muscular atrophy, a rare neuromuscular disease. He has a bachelor's of arts degree in counseling from John Wesley College. In the summer of 2016, Kevan and his friends took a trip across Europe, leaving his wheelchair at home, and his friends carried him for three weeks in a backpack. An avid storyteller, Kevan has authored several books, including a memoir of

While we can all agree that accessibility features are necessary for people with disabilities, the language itself must also be accessible.

LANGUAGE MUST BE ACCESSIBLE TOO!



BY LAUREN AGORATUS, M.A.

THE SCOPE OF THE PROBLEM

Accessibility features such as contrast, recommended fonts, screen readers, etc. will mean nothing if the language is filled with jargon, acronyms, and confusing language. The Centers for Disease Control and Prevention (CDC) notes that health literacy is the single largest barrier to healthcare access. Only 1 in 7 can correctly read their prescription bottle and medication administration errors are the largest cause of preventable hospitalization. For more information on health literacy, see **www.cdc.gov/healthliteracy/index.html**. However, this issue goes beyond healthcare and affects all aspects of the lives of individuals with disabilities

WHAT IS PLAIN LANGUAGE?

The basic elements of plain language include:

- ***Audience and purpose:*** *Consider the skills of your audience and what they may or may not already know.*
- ***Structure:*** *Consider if information needs to be presented in sequence, or perhaps summarized and then provide details.*
- ***Design:*** *Includes font, white space, and visuals such as infographics.*
- ***Expression:*** *Avoid jargon and lengthy sentences.*
- ***Evaluation:*** *Have someone review or use a checklist to edit.*

HOW TO USE PLAIN LANGUAGE

The Center for Plain Language provides templates and tools *(see Resources)*. These include introductory trainings, software, and writing for specific professions such as science, legal, health etc.

Writing for the Web|Writing Plainly has ten tips on writing online which are:

1. Write for the average reader
2. Organization of material should fit the reader's needs
3. Use headings
4. Use personal pronouns like "you" for a conversational tone
5. Active, rather than passive, voice
6. Short sentences
7. Avoid jargon
8. Leave out excess words
9. Put words in order
10. Don't use multiple levels

The Vera Institute for Justice has information on creating accessible print, web, or even webinars. In addition to plain language, it is suggested to use visually accessible font, white space, color contrast, and graphics.

IMAGE COURTESY PLAINLANUAGENETWORK.ORG

ENSURING MATERIALS USE PLAIN LANGUAGE

Plain language has become such an issue that even Microsoft Word has information readability and accessibility features. Plainlanguage.gov has a checklist to see if a document is in plain language. There is a checklist for written materials as well as one for web content. The Health Sciences Library has tools to test materials for plain language. Finally, the National Institutes of Health has a Plain Language Tool, “Getting Started or Brushing Up”. This tool discusses pre-writing considerations, connecting with readers, presenting information, format/visuals, and testing.

FAMILY FRIENDLY/YOUTH FRIENDLY LANGUAGE

Materials must be in plain language for families and self-advocates. Exceptional Lives has Plain Language Guides for Parents of Kids or Adults with Disabilities. These are online How-to Guides to help parents through many complex processes like creating a specialized education plan, getting SSI benefits, or optimizing health insurance. Plain Language is a key component of accessibility. Youth as Self-Advocates of TX provides basic ideas on youth-friendly language. This includes using clear wording, avoiding jargon, explaining acronyms, and using examples to explain complex ideas. The Parent Center Hub has information for parent centers on creating materials for self-advocates. This includes using examples, plain language, digital tools for readability, and other resources.

THE IMPORTANCE OF PLAIN LANGUAGE

Why is it so important to use Plain Language? The benefits of Plain Language are:

✓ Getting a message out quickly
✓ The message is understandable
✓ Less time spent on explaining

Many of the tips have been consistent regarding Plain Language. Using these tips and tools will enhance readability and accessibility for families and self-advocates.•

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 SPAN Parent Advocacy Network (SPAN) at www.spanadvocacy.org

MAKE IT PLAIN : ENHANCING READABILITY AND ACCESSIBILITY FOR FAMILIES AND SELF-ADVOCATES

PLAIN LANGUAGE ASSOCIATION INTERNATIONAL
What is Plain Language?
https://plainlanguagenetwork.org/plain-language/what-is-plain-language

CENTER FOR PLAIN LANGUAGE
https://centerforplainlanguage.org/learning-training/templates-tools-training

PARENT CENTER HUB
Writing for the Web | Writing Plainly
www.parentcenterhub.org/web-plain
Plain Language Writing: An Essential Part Of Accessibility
www.parentcenterhub.org/plain-language-writing

VERA INSTITUTE FOR JUSTICE
www.vera.org/publications/designing-accessible-resources-for-people-with-disabilities-and-deaf-individuals

UNC HEALTH SCIENCES LIBRARY: TOOL
https://hsl.lib.unc.edu/health-literacy/plain-language-resources

PARENT CENTER HUB
The Importance of Plain Language
www.plainlanguage.gov/about/benefits
Checklist for Plain Language
www.plainlanguage.gov/resources/checklists/checklist
Why use plain language?
www.plainlanguage.gov/about/benefits

NATIONAL INSTITUTES OF HEALTH: TOOL
www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication/plain-language/plain-language-getting-started-or-brushing

EXCEPTIONAL LIVES
Plain Language Guides for Parents of Kids or Adults with Disabilities
www.exceptionallives.org

TEXAS PARENT TO PARENT
Youth Friendly/Accessible Language
www.txp2p.org/Media/other-articles/Youth_Friendly_KASA.pdf

As the world celebrates what would have been Eunice Kennedy Shriver's 100th birthday on July 10, 2021, I reflect on my dear mentor and friend. Mrs. Shriver – which is what I will always call her – is most famous for founding Special Olympics and is widely known as the younger sister of former U.S. President John F. Kennedy. She was highly educated, receiving her degree in sociology from Stanford University. Following her graduation, Mrs. Shriver worked in government and as a social worker in adult and youth settings. She made an impression on countless people, and the world mourned her when she passed away on August 11, 2009. What some people may not know is how her life's work continues to transform the public health arena for people with intellectual disabilities.

PHOTOS PROVIDED BY RENEE DEASE

EUNICE KENNEDY SHRIVER'S LEGACY

BY RENEE DEASE

I first met Mrs. Shriver when she brought me on board as a receptionist at Special Olympics in 1978. She was an influence in my life for over 30 years, continuously pushing me to be the best version of myself, from teaching me to study and achieve my education, to advising me on raising my own daughter. Today, I am one of the very few current Special Olympics employees to have known Mrs. Shriver, both on a personal and professional level. She was a strong, willful, and candid leader. But to me, and to others with intellectual disabilities, Mrs. Shriver was caring, attentive, and soft-hearted. No matter what important issues Mrs. Shriver had going on in her life, she always took time to sit down and listen to me. She valued my opinion, and when we first began to work together, she sought my insight into the creation of various Special Olympics programs.

GO OUT AND BE YOUR BEST: "On the anniversary of Mrs. Shriver's 100th birthday, I am proud to represent an organization that celebrates her legacy of inclusion and her commitment to the health and wellness of children and adults with intellectual disabilities."

Many Special Olympics athletes felt that they could always rely on Mrs. Shriver to truly listen to them. I witnessed her ability to listen to athletes and to understand the health disparities encountered by individuals with intellectual disabilities. In 1993 her own sister, Rosemary, who lived most of her adult life with an intellectual disability, received a routine dental check-up that resulted in a rushed diagnosis. Mrs. Shriver recognized that Rosemary's doctors were not trained to specifically treat a patient with an intellectual disability, and she was not willing to accept their findings. The family sought out a second opinion from a pediatric special needs dentist named Dr. Steven Perlman, who provided an alternative treatment plan and oral rehabilitation in line with Rosemary's health needs.

Mrs. Shriver became deeply invested in the health of people with intellectual disabilities, and after Rosemary's successful treatment, she enlisted the help of Dr. Perlman and a group of other medical professionals to create a program that would provide health screenings for all athletes with intellectual disabilities. In 1993, at the Massachusetts State Games, this group of medical professionals from Boston University performed health screenings for every athlete at the competition. It was in this moment that I witnessed inclusive health start to become a reality for people with intellectual disabilities.

Nearly 30 years ago, a health program that came from the vision and personal experiences of Mrs. Shriver has now delivered over 2-million free health screenings and trained close to 300,000 health professionals and students to treat people with intellectual disabilities. The impact of these screenings on the health and wellness of Special Olympics athletes around the world is significant. These screenings have helped discover undetected health problems, alleviated pain and provided health services that otherwise would not be available to many people with intellectual disabilities. Beyond that, Special Olympics Health programming additionally focuses on the development of children with and without intellectual disabilities, the creation of fitness and nutrition resources for athletes, and yielding athlete engagement by bringing attention to health for athletes and caregivers worldwide.

Special Olympics is currently investing in a life-span approach, serving as health partners for every person with an intellectual disability throughout their life, and partnering with organizations like the CDC and the Golisano Foundation. We are creating a world where people with intellectual disabilities have every opportunity to be healthy and take full advantage of the same health programs and services available to people without intellectual disabilities.

None of this would be possible without Mrs. Shriver's vision. On the anniversary of Mrs. Shriver's 100th birthday, I am proud to represent an organization that celebrates her legacy of inclusion and her commitment to the health and wellness of children and adults with intellectual disabilities around the world. Her advice to every Special Olympics athlete was to "go out and be your best," and we know that to do your best, you must feel your best. To learn more about inclusive health practices for children and adults with intellectual disabilities visit **www.specialolympics.org/inclusive-health** •

ABOUT THE AUTHOR:

Renee Dease joined Special Olympics over 40 years ago. Currently, her work focuses on athlete leadership and amplifying the health stories of Special Olympics athletes worldwide. She has served on Special Olympics D.C. Board of Directors for 10 years. Renee earned her associate degree in Liberal Studies and is currently pursuing a bachelor's degree in Sociology. She is fond of creative writing, poetry, and attending theatrical performances.


I AM A VETERAN
AND THIS
IS MY VICTORY.

EXCEPTIONAL PARENT • PHYSICIAN • PATIENT • PEOPLE

FROM OUR FAMILIES… TO YOUR FAMILIES

MILITARY
SECTION

KNOW THE LAWS THAT PROTECT YOUR CHILD WITH SPECIAL NEEDS

GOOD IDEA: The IDEA ensures that all children with qualifying disabilities have access to a free and appropriate public education. States have different procedures for implementing the law, but they all must be consistent with the IDEA.

You want to be an effective advocate for your child with special needs. The first step is to understand the laws that are in place to protect children with special needs.

Federal laws regulate special education services (**www.militaryonesource.mil/family-relationships/special-needs/special-education-and-childcare/an-overview-of-special-education**) and make sure schools provide accommodations for children with disabilities. Almost all states now have anti-bullying laws on the books, as well. By understanding these laws and your child's rights, you'll know better how to ensure your child receives fair and equal access to their education.

INDIVIDUALS WITH DISABILITIES EDUCATION ACT

Enacted in 2004, the Individuals with Disabilities Education Act ensures that all children with qualifying disabilities have access to a free and appropriate public education. The law outlines the special education benefit, including individualized special education services. States have different procedures for implementing the law, but they all must be consistent with the IDEA. In accordance with the six basic principles outlined in Part B of the IDEA (**www.militaryonesource.mil/products/part-b-of-the-individuals-with-disabilities-education-act-fact-sheet-194**), schools must:

- ***Provide free and appropriate public education.*** *Schools are required to provide an education at public expense, under public supervision and direction.*
- ***Conduct an evaluation.*** *Schools must gather the information necessary to help determine the child's educational needs and guide decision making about appropriate educational programming.*
- ***Produce an individualized education program.*** *To ensure that the child's individual needs are met, schools must create a written statement of the educational program designed for the child.*
- ***Provide the least restrictive environment.*** *Children with a disability are entitled by law to receive an appropriate education designed to meet their special needs. They must be educated with their nondisabled peers unless the nature of the disability is such that they cannot achieve in a general education classroom, even with supplementary aids and supports.*
- ***Offer opportunities for meaningful participation.*** *Schools must provide opportunities for parents and students, when appropriate, to get involved throughout the special education process.*
- ***Implement procedural safeguards.*** *Procedural safeguards ensure that children's and parental rights are protected and establish clear steps to address disputes. Procedural safeguards guarantee that parents can participate in meetings, examine all educational records and obtain an individual educational evaluation.*

The IDEA's Part B also establishes the educational requirements for children with a disability from ages 3 to 21. To further explore how this legislation helps to safeguard your child's rights, visit the IDEA website (**https://sites.ed.gov/idea**), which covers such topics as discipline, early intervention services, identification of specific learning disabilities, individualized education programs, dispute resolution and much more. To learn about due process in disputes about special education services, see the fact sheet, Resolving Concerns With a Child's Special Education Services at **www.militaryonesource.mil/products/resolving-concerns-with-a-childs-special-education-services-fact-sheet-956**.

AMERICANS WITH DISABILITIES ACT

The Americans with Disabilities Act of 1990 (**www.militaryonesource.mil/health-wellness/wounded-warriors/the-road-ahead/understanding-the-americans-with-disabilities-act**) provides civil rights protections to individuals with disabilities. The ADA (**www.militaryonesource.mil/products/americans-with-disabilities-act-fact-sheet-180**) defines an individual with a disability as "a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment or a person who is perceived by others as having such an impairment." The ADA does not specifically name all of the impairments that are covered.

Title II of the ADA "prohibits discrimination on the basis of disability by public entities, including public elementary, secondary and postsecondary schools, regardless of whether they receive federal financial assistance. Title II requires that qualified individuals with disabilities, including students, parents and other program participants, are not excluded from or denied the benefits of services, programs or activities of a public entity, or otherwise subjected to discrimination by a public entity, by reason of a disability."

At the Department of Justice's ADA website (**www.ada.gov**), you'll find the full text of the ADA and additional information about the act, including lists of questions and answers about child care centers and the ADA and the Amendments Act of 2008 for Students with Disabilities Attending Public Elementary and Secondary Schools.

SECTION 504 OF THE REHABILITATION ACT OF 1973

Section 504 of the Rehabilitation Act of 1973 protects the rights of people with disabilities in programs and activities that receive federal financial assistance, including federal funds. Public school districts, institutions of higher education and other state and local education agencies may all be recipients of these funds.

Section 504 helps children with disabilities access school services by requiring schools to provide accommodations and modifications. But, unlike IDEA, it does not provide for an individualized education program. Even if a child does not qualify for special education services under the IDEA, he or she may qualify for special accommodations under this law. For example, a child who must use a wheelchair but does not require special education services could receive accommodations under Section 504.

The regulations implementing Section 504 in the context of educational institutions appear at 34 C.F.R. Part 104 (**www2.ed.gov/policy/rights/reg/ocr/edlite-34cfr104.html**). This comprehensive list of more than 40 common questions and answers about Section 504 (**www2.ed.gov/about/offices/list/ocr/504faq.html**) and the education of children with disabilities further explain how this legislation protects your child's rights.

ANTI-BULLYING LAWS

The federal government's anti-bullying website defines bullying as unwanted, aggressive behavior among youth that involves a real or perceived power imbalance and is repeated multiple times or is likely to repeat. Making threats, spreading rumors, physically or verbally attacking someone, and deliberately excluding another person from a group all constitute bullying. In recent years, bullying has become the subject of increased media attention, particularly as technology and social media websites have given rise to "cyberbullying," occasionally with tragic consequences.

Every state in the nation addresses anti-bullying. Using an interactive map (**www.stopbullying.gov/resources/laws**) at the StopBullying website, you can research your own state's laws and policies and find out more about the 13 key components of state anti-bullying legislation, including specification of prohibited conduct, development and implementation of local education agency policies, and training and preventive education.

The website also includes guidance prepared especially for kids, including "Facts about Bullying," "What You Can Do," and more than a dozen "webisodes" (cartoons that portray bullying situations and show kids how to address bullying) with accompanying quizzes.

SCHOOL POLICIES

Your school may have a policy related to discrimination, harassment or bullying. Familiarize yourself with your school's policy by reading the parent handbook or policy manual. If you can't find any information in the parent handbook, ask your school for a copy of its policy.

For more detailed information on the range of laws protecting children with disabilities, you may be interested in the Department Of Justice's Guide to Disability Rights Laws (**www.ada.gov/cguide.htm**).

WHAT TO DO WHEN YOU HAVE CONCERNS ABOUT SCHOOL IMPLEMENTATION

The Resolving Concerns With a Child's Special Education Services (**www.militaryonesource.mil/products/resolving-concerns-with-a-childs-special-education-services-fact-sheet-956**) fact sheet outlines the steps parents and guardians can take if they disagree with their children's school on any issue involving the special education program.

You can find additional resources and answers to your questions about your child's rights within special education by contacting your installation EFMP Family Support provider (**https://installations.militaryonesource.mil/?looking-for-a=program/program-service=16/focus=program**) or your installation legal office (**https://installations.militaryonesource.mil/?looking-for-a=program/program-service=40/focus=program**).

Military OneSource special needs consultants can also answer your questions and concerns about the care and education of your child or adult family member with special needs. Call 800-342-9647.

– Military OneSource

DISABILITY HOUSING GRANTS FOR VETERANS

We offer housing grants for Veterans and service members with certain service-connected disabilities so they can buy or change a home to meet their needs and live more independently. Changing a home might involve installing ramps or widening doorways. Find out if you're eligible for a disability housing grant — and how to apply.

GRANT ELIGIBILITY FOR YOUR PERMANENT HOME

Can I get a Specially Adapted Housing grant? You may be able to get an SAH grant if you're using the grant money to buy, build, or change your permanent home (a home you plan to live in for a long time) and you meet both of the requirements listed below.

Both of these must be true. You:

- *Own or will own the home, and*
- *Have a qualifying service-connected disability*

Qualifying service-connected disabilities include:

- *The loss or loss of use of more than one limb*
- *The loss or loss of use of a lower leg along with the residuals (lasting effects) of an organic (natural) disease or injury*
- *Blindness in both eyes (with 20/200 visual acuity or less)*
- *Certain severe burns*
- *The loss, or loss of use, of one lower extremity (foot or leg) after September 11, 2001, which makes it so you can't balance or walk without the help of braces, crutches, canes, or a wheelchair*

Note: Only 120 Veterans and service members each fiscal year (FY) can qualify for a grant based on the loss of one extremity after September 11, 2001, as set by Congress. A fiscal year runs from October 1 through September 30. If you qualify for, but don't receive, a grant in the current fiscal year because the cap has already been reached, you may be able to use this benefit in future years.

HOW MUCH FUNDING DOES AN SAH GRANT OFFER?

If you qualify for an SAH grant, you can get up to $100,896 for FY 2021. This is the current total maximum amount allowed for SAH grants.

Can I get a Special Home Adaptation (SHA) grant? You may be able to get an SHA grant if you're using the grant money to buy, build, or change your permanent home (a home you plan to live in for a long time) and you meet both of the requirements listed below.

Both of these must be true:

- You or a family member own or will own the home, and
- You have a qualifying service-connected disability

Qualifying service-connected disabilities include:

- The loss or loss of use of both hands
- Certain severe burns
- Certain respiratory or breathing injuries

HOW MUCH FUNDING DOES AN SAH OFFER?

If you qualify for an SHA grant, you can get up to $20,215 for FY 2021. This is the current total maximum amount allowed for SHA grants.

Do I have to use the total grant amount this year? No. If you're eligible for an SAH or SHA grant, you can use money from your grant up to 6 different times over your lifetime.

Depending on the adaptations you need, and the bid from your builder, you can use as much or as little of your grant as you need this year. If you don't use the full amount, you can use more money from the grant in future years.

We may adjust the total maximum amount each year based on the cost of construction. You may receive up to the current total maximum amount for the last year you use the grant.Learn more about how to apply for a housing grant at www.va.gov/housing-assistance/disability-housing-grants/how-to-apply

GRANT ELIGIBILITY FOR YOUR PERMANENT HOME

Can I get money to change a family member's home where I'm living? You may be able to get a Temporary Residence Adaptation (TRA) grant if you meet both of the requirements listed below.

Both of these must be true. You:

- *Qualify for an SAH or SHA grant (see above), and*
- *Are living temporarily in a family member's home that needs changes to meet your needs. (To use a TRA grant, you don't have to own the house.)*

How much funding does a TRA grant offer? If you qualify for an SAH grant, you can get up to $40,637 through the TRA grant program for FY 2021.

If you qualify for an SHA grant, you can get up to $7,256 through the TRA grant program for FY 2021.

HOW TO APPLY FOR A DISABILITY HOUSING GRANT

You can apply online right now by going to our eBenefits website at www.ebenefits.va.gov/ebenefits/about/feature?feature=sah-grant

You'll need to sign in to eBenefits with your DS Logon basic or premium account. If you don't have a DS Logon account, you can register for one on the site. Learn more about how to apply for a housing grant at www.va.gov/housing-assistance/disability-housing-grants/how-to-apply

Learn more about the design options and other information in our housing design handbook.

Read the Guide for Specially Adapted Housing and Special Housing Adaptation Projects (PDF) at https://www.benefits.va.gov/HOMELOANS/documents/docs/sah_handbook_for_design.pdf

Watch these videos to learn more about the SAH and SHA grant program:

- *Eligibility requirements for VA's adaptive housing grant program (YouTube) at* www.youtube.com/watch?v=AKZjGmvJJ6c
- *Specially adapted housing program for disabled Veterans (YouTube) at* www.youtube.com/watch?v=gbJSFFS4z3o
- *VA's adaptive housing grants for disabled Veterans (YouTube) at* www.youtube.com/watch?v=EN5QMihyuhY

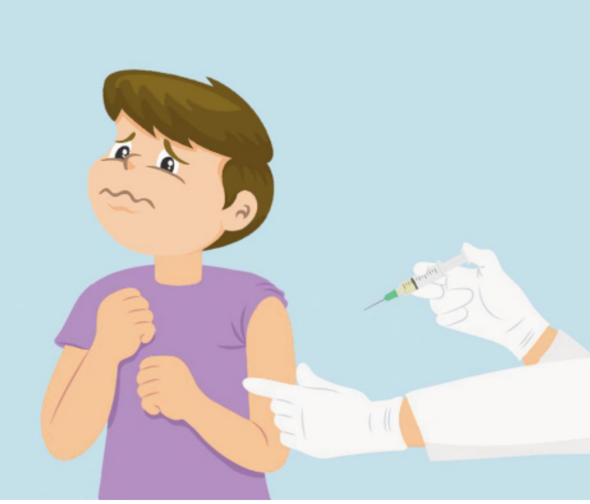
– U.S. Department of Veterans Affairs

PUZZLES & CAMO SHELLY HUHTANEN

Above and Beyond for Health

Broden was surrounded by a circle of support. As I jogged around the table to get to one side of the table to help with Broden, LTC Hanna did the count down, "Ok, let's go, do it." Again, Broden screamed, but immediately after, we yelled, "All done!" and then clapped and cheered for him. He did it, but it took a small caring village to get there.

It was finally Broden's turn to get the COVID-19 vaccine. He was the only member of our household that had not been vaccinated and we were anxiously awaiting when it would be available for him to receive at Fort Jackson. Our initial concerns were logistics and ensuring that there were staff available who were patient and willing to work with us. Broden does not like needles and it usually takes a small team to get him vaccinated. The last time we were able to draw blood from him was after he was put under for dental work. As usual, we would be at the mercy of the medical team administering the shot and when we were notified that Broden was now eligible to receive the vaccination, my anxiety level began to rise.



CALLING THE SHOTS: Broden does not like needles and it usually takes a small team to get him vaccinated. When we were notified that he was now eligible to receive the vaccination, my anxiety level began to rise.

My initial worry was how we were going to keep him calm once he saw the needle and then what was our back-up plan if I was unable to hold him long enough for the injection. I then thought about how in the world were we going to get him into the facility the second time with him knowing what happened the first time he entered the vaccination site. Lastly, I was concerned about him communicating to us on how he felt after the vaccination. Would he be able to tell us that his arm hurt or if he felt achy after receiving the shot? All of these issues ran through my mind as we started to plan the logistics of how to get Broden fully vaccinated.

With the coordination of the medical clinic, we were able to schedule a time at the end of the day when the vaccination facility would have the least amount of traffic. The medical commander, COL Hall, connected us with LTC Hanna since he ran the vaccination site. Mark talked with LTC Hanna beforehand to notify him of Broden's diagnosis so he would be prepared for what may lay ahead.

Mark was not available for the first vaccination and I would possibly be relying on medical staff to assist for the first injection. As we walked down the hall into the large room, Broden seemed to be unaware of what was going to happen. LTC Hanna was waiting for us and brought us over to the table. The room was vacant and there were only a few staff left at the site. LTC Hanna pulled me aside to tell me he also had a son on the spectrum. He understood that every child is different, but we would see how far we could get with as little restraint as possible. I agreed with him. Broden sat on the stool and seemed leery, but was willing to comply. LTC Hanna explained to him that the alcohol pad was to clean the area, Broden started to yell once it touched his skin. I nervously looked up at LTC Hanna and I could tell from his facial expression that this would be a tricky operation.

We walked over away from Broden and conjured up a plan. I would hold Broden and then once he was stable, LTC Hanna would do the injection. With Broden's strength at 15 years old, we quickly realized that this plan wouldn't work. With Mark tied up in a meeting, I asked LTC Hanna if COL Hall could come over. We have become good friends and she's very calm. After speaking to her on the phone, COL Hall arrived minutes later to assist. All of us were placed around Broden. It was LTC Hanna, COL Hall, and me with another helper. I went to hug Broden, but he immediately slipped out of my hands. LTC Hanna swooped Broden up into a bear hug as all of us told the person who was injecting him, "Do it now! Do it now!" Broden let out a scream and then once the shot was in, he let Broden go. I could tell from the look on LTC Hanna's face that it was something he didn't want to do, but needed to do. He quickly left the room while COL Hall and I were comforting Broden.

"You did good, Broden. We're halfway there." Broden laid his cheek against COL Hall's cheek as she praised him. As we walked out the door, LTC Hanna came by and gave Broden a fist bump and assured me that he would be there in two weeks to help with the second dose.

We decided to plan Broden's second dose on a Saturday morning so we could watch him carefully for two days to monitor his response. Mark and I showed up at the facility prepared for some resistance because we knew he would remember what happened there two weeks prior. I look over and COL Hall and her husband, Frank, were there. I soon realized they were there to support Broden. All of us walked down the hall and I could tell that Broden started to look around. A staff member told us we would be doing the last shot in a small room, off to the side for privacy, since they were vaccinating trainees in the main room. Broden started to vocally protest when Mark motioned him to sit on one of the stools in the room. Frank pulled out a unicorn he had made at a craft table to take his mind off of what was about to happen. LTC Hanna ran in and Mark said, "Alright, how do you want to do it?" After a quick discussion on logistics, everyone was in place. This time, Mark was there to help hold Broden in place.

> "These are the moments when I am reminded that sometimes the kindness of others may never feel fully repaid, but that is what it feels like to experience true grace."

Broden was surrounded by a circle of support. As I jogged around the table to get to one side of the table to help with Broden, LTC Hanna did the count down, "Ok, let's go, do it." Again, Broden screamed, but immediately after, we yelled, "All done!" and then clapped and cheered for him. He did it, but it took a small caring village to get there. I thanked LTC Hanna profusely. If it wasn't for his caring heart, I don't think it would have run as smoothly as it did. I thanked COL Hall and she said, "Everyone has different needs and it is our job to meet them to ensure everyone gets what they need. Shelly, this is what we do."

I felt so relieved at that moment. I didn't know how I could ever repay them for their care and persistence to get this done for Broden. Not only were they sensitive to Broden, but they were also sensitive to my needs as his mom.

As we all walked out of the facility to the parking lot, I turned to Frank, "You didn't need to come, Frank. It's a Saturday." He turned to me with tears in his eyes, "Of course we are going to be here to support you." My heart was full and the only words I could muster were, "Thank you." These are the moments when I am reminded that we are not alone and sometimes the kindness of others may never feel fully repaid, but then again, that is what it feels like to experience true grace. •

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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