EP CELEBRATES ITS 50TH YEAR!

EXCEPTIONAL PARENT

PHYSICIAN • PATIENT • PEOPLE

EP MAGAZINE 1971 2021 50 YEARS ANNIVERSARY

EXCEPTIONAL PARENT
MAGAZINE
JUNE 2021
$7.95

AN EP SPECIAL EDITION:

HONORING EP'S HERO ADVOCATES

AADMD • PEOPLE WITH DISABILITIES:

AN HISTORICAL PERSPECTIVE

ANNIVERSARY ISSUE!

NEW! • INTRODUCTION TO EP's

SLEEP SERIES

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE & DENTISTRY
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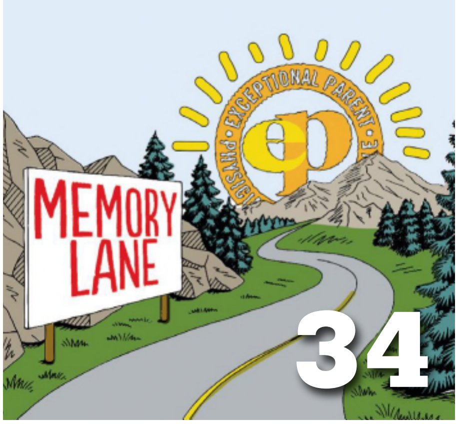
PLUS • PART I

A BRIEF HISTORY OF SPECIAL EDUCATION

CONTENTS

JUNE 2021 VOLUME 51 ISSUE 6

EP'S 50TH ANNIVERSARY ISSUE



FEATURES

DOLLARS & SENSE
A SPECIAL SECTION

ON OUR COVER

EP Magazine, formerly called *Exceptional Parent*, is celebrating its 50th anniversary of providing an award-winning forum for the disability community. First published in 1971, *EP Magazine* is set to continue its legacy of excellence in reporting, advocating and innovating for people with special needs, their caretakers and their loved ones. *Coverage begins on page 17.*

CONTENTS

JUNE 2021 VOLUME 51 ISSUE 6

DEPARTMENTS

ANCORO IMPARO

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE & DENTISTRY

MILITARY SECTION

MILITARY LIFE

PUZZLES AND CAMO

MILITARY LIFE
58 MILITARY CHILD CARE PROGRAMS
59 EDUCATION DIRECTORY FOR CHILDREN WITH SPECIAL NEEDS
61 SPRING CLEAN YOUR EFMP SCOR
PUZZLES AND CAMO
62 HOPE FOR TOMORROW
By Shelly Huhtanen

The contents of *EP* magazine's Military Section are not necessarily the official views of, or endorsed by, the United States Government, the Department of Defense, or the Department of the Army. The appearance of advertising adjacent to the Military Section does not constitute endorsement by the United States Government, the Department of Defense, or the Department of the Army of the products or services advertised.

Information and Support for the Special Needs Community

VOLUME 51 ISSUE 6 ▪ ESTABLISHED 1971

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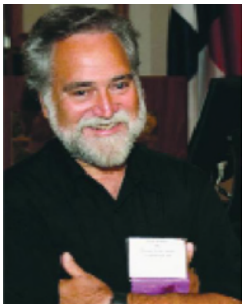
Note from the Editor-in-chief: EP World, Inc. advocates for the dignity of all citizens with disabilities including the use of "people first language" where possible. We do not normally edit articles and submissions that do not reflect this language, therefore, at times, readers might see alternative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

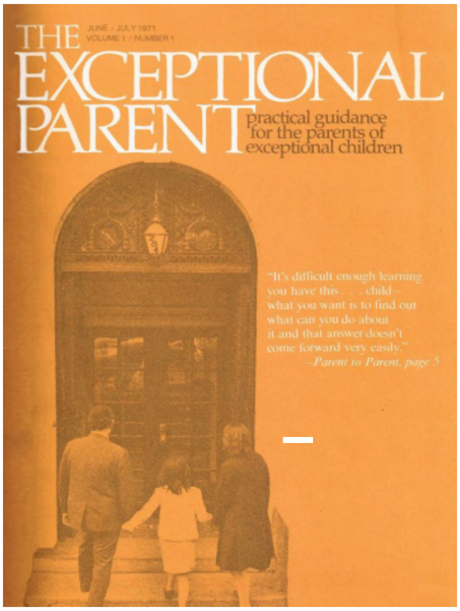
EP magazine neither endorses nor guarantees any of the products or services advertised in the magazine. We strongly recommend that readers thoroughly investigate the companies and products being considered for purchase, and, where appropriate, we encourage them to consult a physician or other credentialed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

Happy Golden Anniversary, EP!

Fifty years ago, there was a growing abundance of parents of children with special health care needs that were already demanding news, information, resources and a portal for plans, hope, preparation and answers. The founders of *Exceptional Parent (EP) Magazine* heard that cry and responded with the publication of the first issue of EP in June/July 1971 (I shared some background information on this in the 2021 EP GUIDE). The maiden issue featured 32 pages and had a warm reception, with many readers wondering, "Why did it take so long?"



Our June 2021 issue celebrates the 50th Anniversary of *EP Magazine,* kicking off a series of commemorative issues to mark this milestone year. A 50th anniversary is symbolized by gold. Gold is just one of over 100 elements in the periodic table, but it stands out over all the metals. Throughout our history, gold has always been used to symbolize power, purity and accomplishment. Those three formed the mission of this journal, which we strive to continue with each issue.



EXCEPTIONAL BEGINNING: The first issue of *Exceptional Parent Magazine*, June/July 1971.

Now called *EP Magazine* (as our logo points out, for "Exceptional Parents, Physician, Patient, People"), our publication has since widened its coverage beyond matters relating to children with special needs to also feature stories, reports and issues affecting young adults to seniors with disabilities or special health care needs.

Over the past 50 years, we have reported, described and celebrated the most significant, game-changing accomplishments of the disability rights movement. Like the "war correspondents" covering the major conflicts involving the United States, we have been right there, often in the fox holes, alongside the heroes – including all the exceptional parents and caregivers, health care professionals, educators and others fully engaged in supporting our community. •

A GOLDEN LEGACY : FIFTY YEARS OF INNOVATION, CHANGE AND TRIUMPH

For this special issue, I have come up with a list (in alphabetical order) of what I think have contributed to the current realities of the disability community. It is provided as a score card and with the understanding that the game is only approaching the bottom of the seventh inning. The list of milestones could have easily gone on for many additional pages.

“504 Sit-in” by Disability Rights Activists • “Nothing about us without us.” • “Spread the Word- To End the Word” • AAIDD published “Intellectual Disability Definition, Diagnosis, Classification, and Systems of Support” • Across America - Supported Employment Program • Adaptive Therapeutic Recreation Specialist certification • Advancement and acceptance of Neuroplasticity • Advances in Neo-Natal Intensive Care Medicine • Advancing the specialty of Behavioral and Developmental Pediatrics • American Academy of Developmental Medicine and Dentistry • American Association of People with Disabilities • American Association on Health and Disability • Americans with Disabilities for Accessible Transportation (ADAPT) • Appearance of actors with disabilities on prime-time television (not portrayed primarily as characters with disabilities) • Assistive Technology Act becomes law • Augmentative Communication • Center for Independent Living • Charlotte Woodward Organ Transplant Discrimination Prevention Act • Closing of Pennhurst State School and Hospital • Congress creates the Office of Disability Employment Policy • COVID-19 and the Death of Michael Hicks • Creation of National Council on Disability • Creation of the National Center on Birth Defects and Developmental Disabilities • Data Collection and Analytics to Influence New Program Initiatives • Development of Parent and Training Information Centers • Developmental Disabilities Nurses Association • Early Intervention Programs • Establishment of Crisis Intervention Team (CIT) training for law enforcement • Establishment of National Association of Dual Diagnosis • Establishment of People First • Establishment of The Office of Rare Disease • Exceptional Parent Magazine • Expansion of Universal Newborn Screening • Family Voices • First Disability Pride Parade, Chicago • Habilitation vs. Rehabilitation Model • Healthcare Extension and Accessibility for Developmentally Disabled and Underserved Population (HEADs Up) Act of 2019 • Impact of oral health on overall health • Individual Educational Plan (IEP) • Investigation of Willowbrook State School • Judge Bazelon Center for Mental Health Law • Justin Dart – organization of Justice for All • Katie Beckett Waiver • Last of “Ugly Laws” repealed • Mainstream and inclusion Classrooms • Montreal Declaration • Movement to recognize “people with disabilities” as a “Medically Underserved Population.” • National Alliance for Direct Support Professionals – Code of Ethics • National Council on Independent Living National Federation of the Blind established dial-up synthetic-speech talking newspaper • National Home of Your Own Alliance • National Leadership Consortium on Developmental Disabilities • National Task Group on Intellectual Disability and Dementia Practices • Not Dead Yet • Olmstead Act; states required to provide services in most integrated settings • Passage of Americans with Disabilities Act (ADA) • Passage of Individuals with Disabilities Education Act (IDEA) • Patient-Centered Medical Home Model • Patient-Centered Outcomes Research Institute • Personal Outcomes – National Council on Quality and Leadership • Person-Centered Thinking • Positive Behavioral Supports • Positive Exposure • Project Accessible Oral Health • Proposal to create “disability competency training” in medical education curriculum • Publication of Christmas in Purgatory • Quality-Adjusted Life Years and The Devaluation of Life with a Disability • Recognition and treatment of Sensory Processing Disorders • Recognition of “Abelism” • Recognition of autism and its growing prevalence • Recognition of Music and Art Therapy • Recognition of negative consequences of Diagnostic Overshadowing • Rehabilitation Act Amendments • Report of the Surgeon General – Closing the Gap • Rise of the Self-Advocate • Road-to-Freedom Tour • Rosa’s Law • Sandra Jensen (Down syndrome) denied heart-lung transplant; decision was reversed • Science of “seating” • Section 504 • Simon Foundation for Continence • Social Model Replaces the Medical Model • Special Olympics; Special Olympics Healthy Athletes Program • State Councils on Developmental Disabilities • Supported Decision Making • Telecommunications Act – resulting in accessible computers, telephone, closed captioning • The Community Imperative • The Fatal Five • Ticket to Work and Work Incentives Improvement Act • Transformation to Competitive Integrated Employment Act • United Nations – Convention on the Rights of Persons with Disabilities • Welcome to Holland - (Emily Kingsley) • WHO International Classification of Functioning

Some of you may see obvious omissions. One example would be The Arc of the United States. We wanted to list the milestones of the last 50 years (in conjunction with our 50th Anniversary). The Arc was founded in 1950 so it predated the publication of *EP Magazine*. My apologies for those that were left out. We would love to hear from EP readers advising us of those who belong on the list.

Reflections of an Orderly and His Duties

Parents of children with special health care needs have long learned the art of emptying "crap" from their surroundings. They strive to discard short-sighted legislation. They are diligent about cleaning up misguided polices and are gifted and skilled in ensuring that insensitivity is properly and effectively flushed.

During a recent weekend, it rained and I thought it was a good opportunity to clean out some files that I haven't looked at in years.

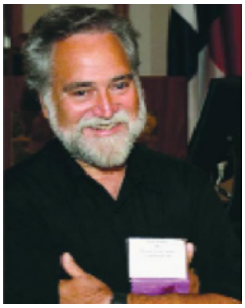
GOLDEN ANNIVERSARY
50 YEARS OF EP
—- 1971 – 2021 ---

While looking at one large envelope labeled "I.D. Badges," I was reminded of some of the numerous jobs I had when I was in college. There was a badge when I worked at Kennedy Airport cleaning the jets. Another badge from the City of New York when I was a vendor selling giant chocolate chip cookies from a cart. I found my I.D. badge from the summer when I worked at Hemisphere '68, the World's Fair held in San Antonio, a dream job as I worked in the Belgium waffle stand. Another summer I spent parking cars at the Astro Dome in Houston. I started to think of some of the other jobs I had in college, not all of them provided me with an I.D. Badge. I worked in my college's snack bar, giving out change to night students buying food from the vending machines. Several summers were spent as a camp counselor. Busing tables at iconic Brooklyn delicatessens. Manning the reception desk in my dorm. Sticking newspapers in plastic bags for the delivery boys. Then of course there was the occasional babysitting gigs, yard cleaning, washing cars, and a host of jobs that provided me with the funds to repair a series of cars that constantly let me down.

I started to throw the badges back into the envelope (no way can you throw that stuff out) and found a badge at the bottom of the envelope. It was my badge from Long Beach Memorial Hospital, and it had the word ORDERLY in bold letters under my name.

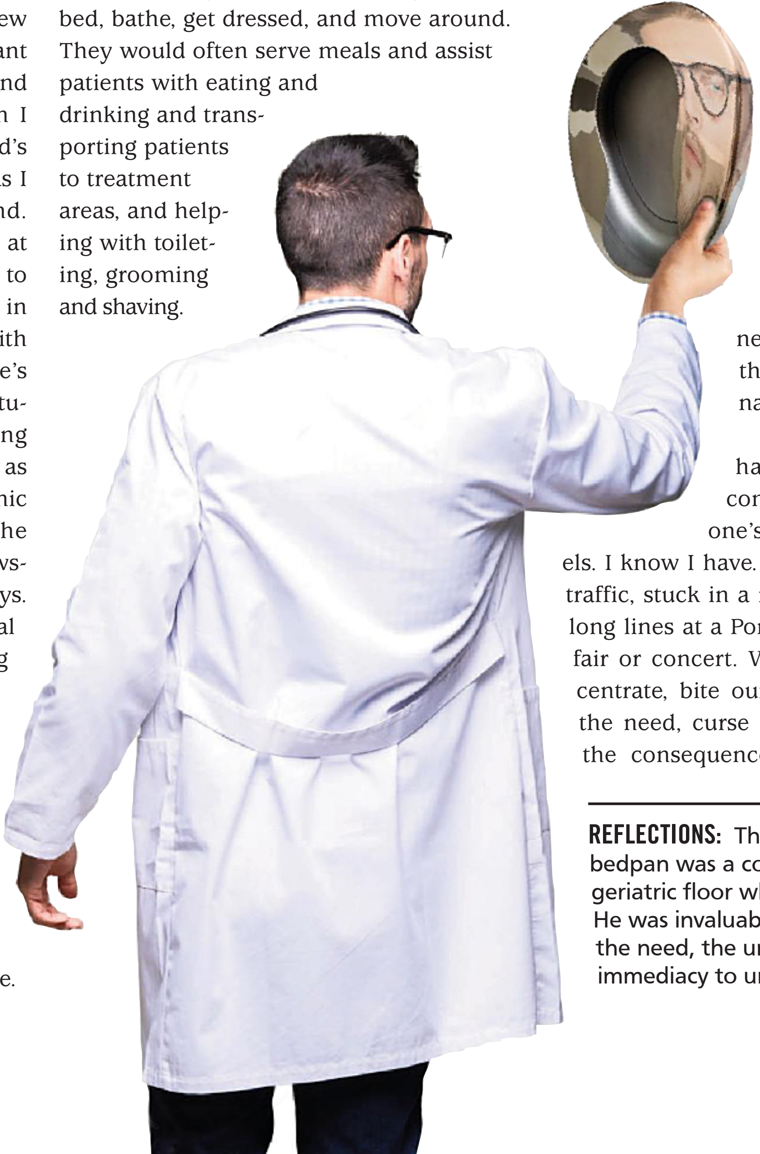
In my senior year of college, I worked full time as a hospital orderly. On the first day, they gave me a white coat, a pager, and an ID badge. It was as close to feeling and looking like a doctor without going through the rigors of eight years of arduous education. The fantasy ended on day two when they gave me a shiny steel bedpan. I realized that all that was standing between my bedpan and a stethoscope were 2,920 days of education.

The "orderly" helped patients get out of bed, bathe, get dressed, and move around. They would often serve meals and assist patients with eating and drinking and transporting patients to treatment areas, and helping with toileting, grooming and shaving.



We also went running after charts and records and provided all the non-medical needs of the individual. For those patients who were unable to be escorted to the bathroom, we provided the bedpan, removing it after it was used and attended to its proper cleaning and sanitizing. The orderly with the bedpan was a common sight on the geriatric floor where I was assigned. Like a soldier and his/her rifle, an engineer and his/her slide rule (a more romantic image than an engineer and his/her laptop), and a cop and his/her nightstick, the orderly and his bedpan was a dynamic couple. He (there were no female orderlies) was also invaluable for those who had the need, the urgency, and the immediacy to urinate and defecate.

I assume everyone has experienced the compelling call to relieve one's bladder and/or bowels. I know I have. We are often stuck in traffic, stuck in a meeting, or waiting in long lines at a Porta-John at an outdoor fair or concert. We gyrate, dance, concentrate, bite our lower lip and curse the need, curse the seconds, and fear the consequences. When completed,



REFLECTIONS: The orderly with the bedpan was a common sight on the geriatric floor where I was assigned. He was invaluable for those who had the need, the urgency, and the immediacy to urinate and defecate.

we feel that all is well with the world. And while many of my patients thanked me for providing them with a feeling of great relief, it was years later that I found out it was actually the vagus nerve that was owed the gratitude.

In those days, we were encouraged to call our patients by their first names, or "mom,' or "pop," with the misguided intention to make them feel it was a personal relationship, that we were almost like family. I was never comfortable with that and always referred to them as "Mrs. Endicott" or "Mr. Nussbaum" or "Professor McBride." I knew I was on the right track when, years later, I read that Maggie Kuhn, the American activist and founder of the Gray Panthers Movement (who was forced out of her job at a company that had a mandatory retirement age of 65) was fond of saying, "The worst indignity is to be given a bedpan by a stranger who calls you by your first name." I remind my medical students and residents that respect is a two-way street.

> "On the first day of being a hospital orderly, they gave me a white coat, a pager, and an ID badge. On day two they gave me a shiny steel bedpan. I realized that all that was standing between my bedpan and a stethoscope were 2,920 days of education."

Bedpans have been around since the first injured and bedridden Roman warrior cried, *"Devo pisciare."*

Bedpans in the 16th and 17th century were made of glazed earthenware. Through the years, pewter, brass, pottery, glass, porcelain, and enamel were also used to make bedpans and urinals.

Florence Nightingale, the Mother of Nursing, carried her fair share of bedpans throughout her career. Even in the 1800's, the task of attending to the bedpan was not embraced by nurses. In 1859, she felt compelled to deliver this harsh message, "If a nurse declines to do these kinds of things for her patient, 'because it is not her business,' I should say that nursing was not her calling."

Fidelindo Lim, a Nursing Professor at the New York University College of Nursing, goes on to explain that *"these kinds of things"* were what Nightingale referred to about nurses emptying the *chamber utensil* and not letting it sit in the room with its contents. The ever-prescient Lady with a Lamp goes on to say with an indictment, "I have known the best and most attentive nurses guilty of this."

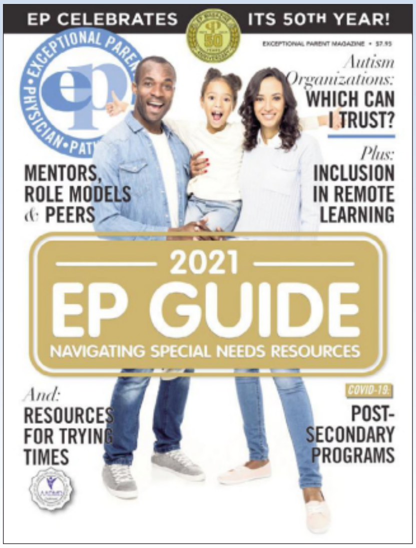
Parents of children with special health care needs have long learned the art of emptying "crap" from their surroundings. They strive to discard short-sighted legislation. They are diligent about cleaning up misguided polices; and they are gifted and skilled in ensuring that insensitivity is properly and effectively flushed.

Visitors to Mount Vernon, the home of George and Martha Washington, can see their personal bedpan on display. While his furniture, swords, clothing and tableware are impressive it's the pewter bedpan that astonishes onlookers. It was misplaced for decades and, when found, put on display in Mount Vernon's museum in 2010. According to Adam Erby, the museum's curator, "The bedpan provides tangible connections not only with the Washingtons, but also with the enslaved house servants who were responsible for emptying the bedpan." •

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

EQUAL EMPLOYMENT OPPORTUNITY COMMISSION ISSUES UPDATED COVID-19 TECHNICAL ASSISTANCE

The U.S. Equal Employment Opportunity Commission (EEOC) recently posted updated and expanded technical assistance related to the COVID-19 pandemic, addressing questions arising under the federal equal employment opportunity (EEO) laws.

The EEOC also posted a new resource (**www.eeoc.gov/federal-laws-protect-you-against-employment-discrimination-during-covid-19-pandemic**) for job applicants and employees, explaining how federal employment discrimination laws protect workers during the pandemic. These publications are provided to help employees and employers understand their rights and responsibilities at work during the pandemic.

The expanded technical assistance provides new information about how the Americans with Disabilities Act (ADA) and the Genetic Information Nondiscrimination Act (GINA) apply when an employer offers incentives for employees to provide documentation or other confirmation of vaccination when an employee gets a vaccine in the community or from the employer or its agent. The technical assistance answers COVID-19 questions only from the perspective of the EEO laws. Other federal, state, and local laws come into play regarding the COVID-19 pandemic for employers and employees.

"The updated technical assistance released today addresses frequently asked questions concerning vaccinations in the employment context," said EEOC Chair Charlotte A. Burrows. "The EEOC will continue to clarify and update our COVID-19 technical assistance to ensure that we are providing the public with clear, easy to understand, and helpful information. We will continue to address the issues that were raised at the Commission's recent hearing on the civil rights impact of COVID-19."

The new resource for job applicants and employees provides basic information about how federal employment discrimination laws help workers who are being harassed; who need extra protection against getting sick; who are not being allowed to work; or who need a modification of their employer's COVID-19 safety requirements.

These two publications follow an EEOC hearing on April 28 (**www.eeoc.gov/meetings/meeting-april-28-2021-workplace-civil-rights-implications-covid-19-pandemic**) on the impact of the COVID-19 pandemic on civil rights in the workplace at which the EEOC heard from a wide range of experts. They were prepared prior to the CDC's new guidance for fully vaccinated individuals (**www.cdc.gov/coronavirus/2019-ncov/vaccines/fully-vaccinated-guidance.html**) issued on May 13, 2021, and do not specifically address that new guidance. As new developments occur, the EEOC will consider any impact they may have on EEOC's COVID-19 technical assistance and will provide additional updates and assistance to the public as needed.

The EEOC advances opportunity in the workplace by enforcing federal laws prohibiting employment discrimination. More information is available at **www.eeoc.gov**. Stay connected with the latest EEOC news by subscribing to email updates at **https://public.govdelivery.com/accounts/USEEOC/subscriber/new**.

WORKING IT OUT : KEY UPDATES TO THE TECHNICAL ASSISTANCE

Federal EEO laws do not prevent an employer from requiring all employees physically entering the workplace to be vaccinated for COVID-19, so long as employers comply with the reasonable accommodation provisions of the ADA and Title VII of the Civil Rights Act of 1964 and other EEO considerations. Other laws, not in EEOC's jurisdiction, may place additional restrictions on employers. From an EEO perspective, employers should keep in mind that because some individuals or demographic groups may face greater barriers to receiving a COVID-19 vaccination than others, some employees may be more likely to be negatively impacted by a vaccination requirement.

Federal EEO laws do not prevent or limit employers from offering incentives to employees to voluntarily provide documentation or other confirmation of vaccination obtained from a third party (not the employer) in the community, such as a pharmacy, personal health care provider, or public clinic. If employers choose to obtain vaccination information from their employees, employers must keep vaccination information confidential pursuant to the ADA.

Employers that are administering vaccines to their employees may offer incentives for employees to be vaccinated, as long as the incentives are not coercive. Because vaccinations require employees to answer pre-vaccination disability-related screening questions, a very large incentive could make employees feel pressured to disclose protected medical information.

Employers may provide employees and their family members with information to educate them about COVID-19 vaccines and raise awareness about the benefits of vaccination. The technical assistance highlights federal government resources available to those seeking more information about how to get vaccinated.

NATIONAL DISABILITY EMPLOYMENT AWARENESS MONTH THEME IS 'AMERICA'S RECOVERY: POWERED BY INCLUSION'

The U.S. Department of Labor has announced the theme for 2021 National Disability Employment Awareness Month is "America's Recovery: Powered by Inclusion."

Held each October, the annual commemoration raises awareness about disability employment issues, and celebrates the many and varied contributions of America's workers with disabilities.

Selected by the department's Office of Disability Employment Policy (**www.dol.gov/agencies/odep**), the theme's annual spring announcement helps the nation's employers, disability advocates and other organizations plan their observances. As ODEP celebrates its 20th anniversary in 2021, it encourages all types of employers and community organizations, advocacy groups and schools to participate.

"Our national recovery from the pandemic cannot be completed without the inclusion of all Americans, in particular people with disabilities," said U.S. Secretary of Labor Marty Walsh. "Their contributions have historically been vital to our nation's success, and are more important today than ever. We must build an economy that fully includes the talent and drive of those with disabilities."

"America's Recovery: Powered by Inclusion" is a theme that reflects our commitment to an inclusive recovery, one in which those of us with disabilities have full access to economic opportunity and – if needed – the accommodations and supports that allow us to contribute our skills and talents," said Deputy Assistant Secretary of Labor for Disability Employment Policy Jennifer Sheehy.

ABOUT THE OFFICE OF DISABILITY EMPLOYMENT POLICY

ODEP
Office of Disability Employment Policy

Office of Disability Employment Policy (ODEP) is the only non-regulatory federal agency that promotes policies and coordinates with employers and all levels of government to increase workplace success for people with disabilities. Visit **www.dol.gov/agencies/odep**

WHAT'S HAPPENING

AUTISM SOCIETY OF AMERICA ENCOURAGES AUTISM COMMUNITY TO VACCINATE ELIGIBLE ADOLESCENTS

On May 10, 2021, the Food and Drug Administration (FDA) authorized use of the Pfizer-BionTech COVID-19 vaccine for 12-15 year-olds. The Autism Society of America and leading disability organizations encourage all eligible individuals and their families to protect themselves and others by getting vaccinated.

In early December 2020, the Autism Society led a collaborative effort, with other national disability organizations calling for people with autism and other developmental disabilities to be prioritized for COVID-19 vaccination (www.autism-society.org/news) as the inoculation plan began. Over the last several months, the Autism Society has worked alongside the Centers for Disease Control and Prevention (CDC) and other partners to educate the community about the COVID-19 vaccine to quell vaccine myths and hesitancy in the effort to keep our community safe. The American Academy of Pediatrics (https://pediatrics.aappublications.org/content/pediatrics/early/2021/05/11/peds.2021-052336.full.pdf) and the CDC (www.cdc.gov/coronavirus/2019-ncov/vaccines/recommendations/adolescents.html) have independently reviewed the data and the FDA's decision, and recommend vaccination for everyone 12 years of age and older. The Autism Society of America encourages parents to consult their child's physician when determining if the COVID-19 vaccine is recommended for their eligible child.

SOMETHING BREWING: The American Academy of Pediatrics and the CDC have recommend vaccination for everyone 12 years of age and older.

"Recent data proves that having an intellectual disability was the strongest independent risk factor (https://catalyst.nejm.org/doi/full/10.1056/CAT.21.0051) other than age for Covid-19 mortality," stated Christopher Banks, President and CEO of the Autism Society of America. "In addition to this data, autistic individuals are more likely to have comorbidities and/or live-in congregated settings contributing to death rates being five times higher for people with intellectual disabilities than the general public."

Pfizer-BioNTech announced (www.pfizer.com/news/press-release/press-release-detail/pfizer-biontech-announce-positive-topline-results-pivotal) that participants aged 12-15 years old demonstrated 100% efficacy and robust antibody responses in a Phase 3 clinical trial. The trial enrolled over 2,200 adolescents 12 to 15 years old in the United States. In the trial, 18 cases of COVID-19 were observed in the placebo group, while none contracted COVID-19 in the vaccinated group.

"Expanding the use of these vaccines will protect vulnerable individuals and get us closer to ending this pandemic," stated Dr. Wendy Ross, director of the Center for Autism and Neurodiversity at Jefferson Health (https://hospitals.jefferson.edu/departments-and-services/center-for-autism-and-neurodiversity.html) and member of the Autism Society's Panel of Professional Advisors.

Adolescents are less likely to experience severe symptoms of COVID-19, however the risk is higher among Black and Hispanic youth (www.kff.org/policy-watch/covid-19-vaccines-for-12-15-year-olds-considerations-for-vaccine-roll-out) compared to their White counterparts. The American Academy of Pediatrics (AAP) also urges teens to get the COVID-19 vaccine as soon as it is available to them, especially due to the rise in COVID-19 variant cases.

The COVID-19 vaccine is our best hope for ending the pandemic that has tragically affected the world, and disproportionately impacted the autism community with added challenges throughout the last fourteen months. For over a year, interrupted routines, virtual learning, activity program closures, and more protective measures have impacted our youth, contributing to isolation and mental health issues. Continued scientific research shows that all of the COVID-19 vaccines are highly effective at preventing people from getting COVID-19, in addition to serious illness, hospitalization, and death. The CDC states that COVID-19 vaccines will have "the most intensive safety monitoring in U.S. history" (www.cdc.gov/coronavirus/2019-ncov/vaccines/safety/safety-of-vaccines.html). Lastly, the CDC released updated guidelines (www.cdc.gov/coronavirus/2019-ncov/vaccines/fully-vaccinated-guidance.html) stating that fully vaccinated individuals no longer need to wear a mask or physically distance in any setting – indoors or outdoors – except where required by federal, state, local, tribal, or territorial laws, rules, and regulations, including local business and workplace guidance.

Find a COVID-19 vaccine near you at vaccines.gov *or by texting your zip code to 438829.*

ABOUT THE AUTISM SOCIETY

AUTISM SOCIETY
Improving the Lives of All Affected by Autism

The Autism Society is the nation's oldest leading grassroots autism organization and exists to improve the lives of all affected by autism. Annually, the Autism Society and its 75 local affiliates serve over 600,000 individuals impacted by autism through education, advocacy, information and referral services, support, and providing community inclusion and acceptance at the national, state and local levels. For more information, go to www.autism-society.org, Facebook, Instagram or Twitter.

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AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE & DENTISTRY

GOLDEN ANNIVERSARY
50 YEARS OF EP
—- 1971 – 2021 ---

"Having a disability shapes a person's life, but it is not their total destiny."
– Senator Robert Dole

People with Disabilities: An Historical Perspective

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

George Orwell reminds us that "the most effective way to destroy people is to deny and obliterate their own understanding of their history." This article was conceived with the belief that when we know our history, we can proceed with the understanding that the path to the future is laden with landmines. Landmines that can dismantle and derail the road to success, especially for people with disabilities.

"**Disability has always been, and likely always will be, a part of the human condition** *(emphasis added)*… But the public, and many in the medical community, can underestimate the lives of people with disabilities… 'there's a lot of us roaming around with significant disabilities and who feel we have a pretty good quality of life…'" [1]

HISTORICALLY

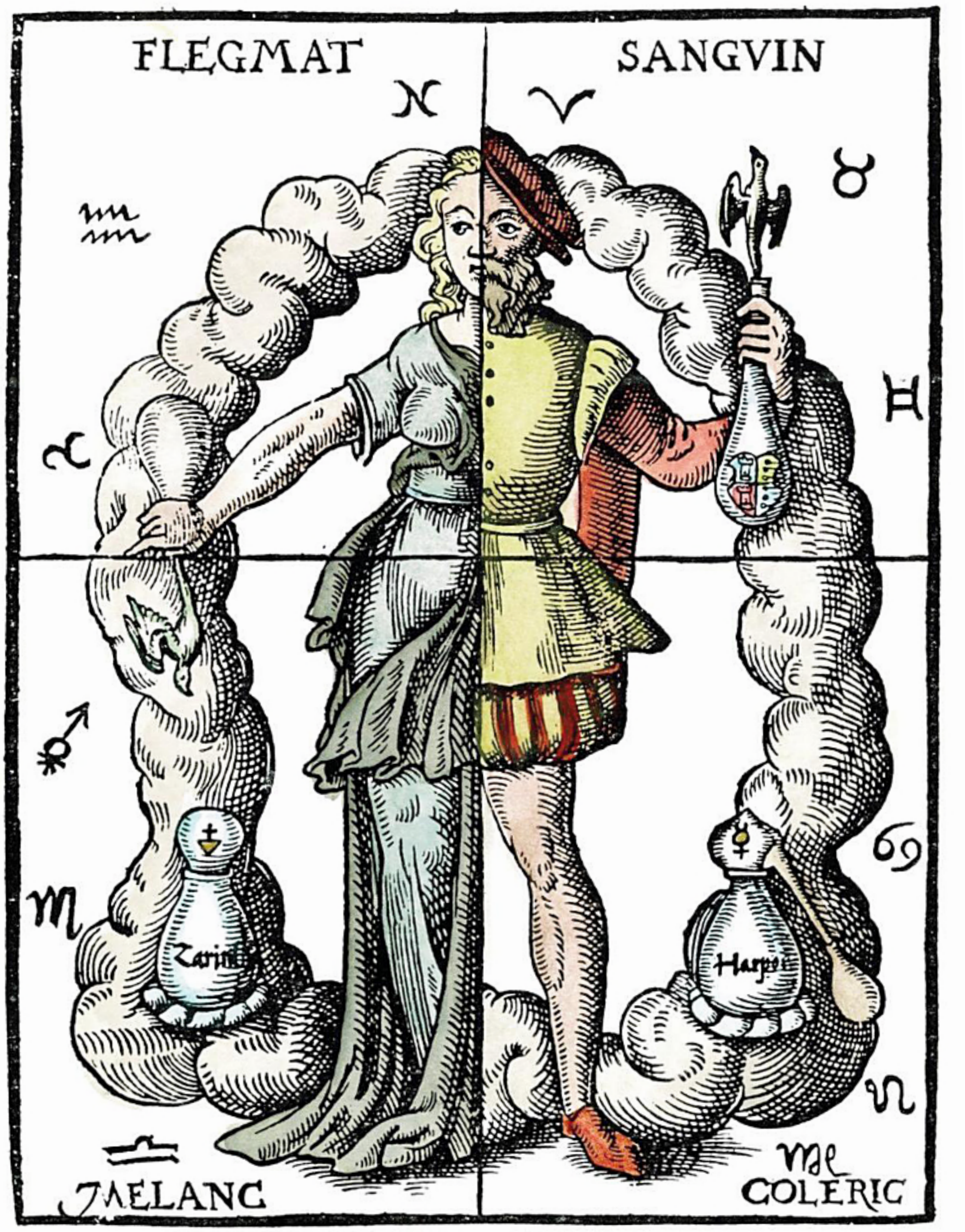
Early Greeks and Romans valued physical perfection. Appearances mattered. Racial and physical differences were seen as marks of inferiority.

"To expose" meant to leave one out in the weather to die. Exposing young children with severe disabilities was a common practice in ancient Greece.

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY

AADMD

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



A SENSE OF HUMOR: Hippocrates believed that health involved a balance of the four "humors:" phlegm, blood, black bile and yellow bile. This belief led later physicians to relate mental illness and intellectual disabilities to an imbalance of "black bile."

Living conditions for persons with disabilities were brutal during this period. Some people were able to survive through acts of charity or as objects of curiosity, but most were not as fortunate. Intolerance, sickness, and disregard for persons with disabilities often meant death or a very low quality of life.

The Ancient Era idealized physical and mental perfection. Disability, although common at this time, was viewed as a mark of inferiority. There was fear and obsession with God and the belief that people with disabilities got what they deserved.

Aristotle (384-322 B.C.) wrote "As to exposure and rearing of children, let there be a law that no deformed child shall live." [1]

Medical Viewpoint: Hippocrates (460-377 B.C.) believed that health involved a balance of the four "humors," or basic body substances: phlegm, blood, black bile, and yellow bile. This belief led later physicians to relate mental illness and intellectual disabilities to an imbalance of "black bile." [1]

Jesus (6 B.C.-30 A.D,) is frequently credited with showing kindness and effecting miraculous cures and those who were lame, blind and otherwise disabled. [1]

St. Paul directed Christians to "comfort the feeble minded." [1]

Connection to different time in history: "When leprosy disappeared after the Crusades (1100-1300), the remaining colonies – the leprosaria – were converted to other uses, resembling our present-day institutions. These establishments were soon filled with all types of persons considered deviant: orphans, vagabonds, madmen, incurables, prostitutes, widows, and criminals. These 'cities of the damned' numbered in the thousands, and had the power of 'authority, direction, administration, commerce, police, jurisdiction, correction and punishments' and had at their disposal stakes, irons, prisons and dungeons." [1]

John Calvin (1509 – 1564) implied that people with disabilities were not among the chosen. Disability was either a sin on the part of the person with disabilities or their families and should be separate from the mainstream of society.[1]

Moral viewpoint: Between 1563 and 1601, Queen Elizabeth of England passed a series of laws requiring the state to take care of the "poor and disadvantaged." Basic care was provided for the unemployable poor. Almshouses were established for the aged poor, and workhouses were built for vagrants who refused to work. Many with disabilities were placed in almshouses or workhouses, where the conditions were grim. [2]

The Renaissance (14th to 17th centuries) led to interest in the arts and sciences, leading to advancements in health care and to a better understanding of disabilities.

At times, persons with disabilities were "shipped off" to other lands so that they would no longer pose a burden on their communities. These ships would sail from port to port charging admission to view the strange human cargo. Eventually, the ships would abandon their "passengers" at other ports forcing them to fend for themselves.

During this time, small prisons called "idiot cases" were common in town centers to "keep people disabilities out of trouble." Mostly they served as entertainment for the town's people. [1]

During the 16th century, Christians such as Luther and John Calvin indicated that individuals with intellectual and other disabilities were possessed by evil spirits. Thus, these men and other religious leaders of the time often subjected people with

WOODCUT FROM "QUINTA ESSENTIA" BY LEONHART THURNEISSER, 1574

disabilities to mental and/or physical pain as a means of exorcising the spirits. [2]

The medical model: Around the 18th century, disability was defined as any one of a series of biological deficiencies located in the body. No longer seen as the result of devine intervention, disabilities became a medical issue, requiring the services of trained professionals. Persons with disabilities assumed the ongoing role of patients needing to be cured. [1]

In the 19th century, supporters of social Darwinism opposed state aid to the poor and otherwise disabled. They reasoned that the preservation of the "unfit" would impede the process of natural selection and tamper the selection of the “best” or “fittest” elements necessary for progeny.

This era also saw the beginning of special education and the birth of a scale to measure intelligence by Drs Alfred Binet and Theodore Simon. [1]

Dorothea Dix (1802-1887) was a social reformer who advocated for persons with mental illness and other disabilities. Traveling across the country, she paved the way for needed public institutions. [1]

During this time, “phrenology – the practice of studying the shape of the skull” offered hope in understanding developmental disabilities. Once a highly respected science, it was rejected by the 1840s. [1]

In 1882, Congress passed the Undesirables Act which prevented convicts, paupers, the insane and idiots from entering the United States. This legislation remained in force until 1965. [1]

> “The term ‘developmental disability’ was adopted in the early 1970s to address disability and funding issues in more comprehensive terms. The concept of ‘normalization’ originated in Denmark in the 1950s. This principle helped convince people that individuals with disabilities belong in our communities.”

Eugenics, the study of how to arrange reproduction within a human population to increase the occurrence of heritable characteristics regarded as desirable, was developed largely by Sir Francis Galton in the 1880s as a method of improving the human race. Eugenics was increasingly discredited as unscientific and racially biased during the 20th century, especially after the adoption of its doctrines by the Nazis in order to justify their treatment of Jews, people with disabilities and other minority groups.

“Three Generations of Imbeciles Are Enough”; so wrote Justice Oliver Wendell Holmes, Jr. in *Buck v. Bell*, a 1927 U.S. Supreme court case upholding a Virginia law that authorized the state to surgically sterilize certain “mental defectives” without their consent.

Beginning in the 1930s, Nazi Germany targeted these populations as a drain on public resources. They were referred to as “useless eaters.” The Nazi euthanasia program (code named Akton T4) was the systematic murder of institutionalized people with disabilities. They sterilized 400,000 Germans and exterminated over 200,000 people with disabilities. [1]

Connection to different times in history: A modern parallel can be drawn to our institutions of the 1950s and 1960s, where a larger number of persons were admitted to meet a growing demand for services, resulting in dehumanizing conditions and a poor quality of life.

Olmstead decision: In 1998, the U.S. Supreme Court ruled in Olmstead v. L.C. that under the Americans With Disabilities Act, unjustifiable institutionalization of a person with a disability who, with proper support can live in the community, is discrimination based on a disability.

Social viewpoint: The United Nations General Assembly adopted the Convention on the Rights of Persons with Disabilities (CRPD) in 2007. It was the first major human rights treaty of the 21st century. By 2014, 143 countries had ratified the CRPD, including the countries of North America except the United States. While President Barack Obama signed the CPRD in 2009, the US Senate had failed to ratify it as late as 2014.

Three laws now protect the civil rights of people with disabilities; *The American With Disabilities Act, Section 504 of the Rehabilitation Act and the Affordable Care Act (Obamacare).* [1]

Nevertheless, “…according to new research by the disability charity Scope, **67 percent** *(emphasis added)* of people feel uncomfortable when talking to people with disabilities. This awkwardness stems from ignorance and fear, and the (uncomfortable) truth is we’ll need time, money, and whole lot of effort to change attitudes.” [4]

In addition, the desire to avoid whatever is associated with evil has affected people’s attitudes towards people with disabilities simply because disability is associated with evil. Most of these negative attitudes are mere misconceptions that stem from lack of proper understanding of disabilities and how they affect functioning. “These misconceptions stem directly from the traditional systems of thought, which reflect magical-religious philosophies that can be safely called superstition.” [2]

And further, social attitudes towards persons with disabilities are reflected in the family, which teaches by example customs and institutionalized values. Child-rearing practice tend to predetermine an adult’s behavior towards persons with disabilities. Their findings show that beliefs about illness are influenced by significant early relationships between children and parents that deal with the child’s conformity to adult standards behavior. [2]

MORE RECENTLY

Though used primarily for labeling persons with physical disabilities, the term “handicapped” has been applied to all persons with disabilities and became an increasingly popular term in the middle twentieth century.

Parents of children with disabilities began organizing in the 1930s. The National Association for Retarded Children was founded in 1950; later becoming the National Association for Retarded Citizens and currently the ARC.

The term “developmental disability” was adopted in the early 1970s to address disability and funding issues in more comprehensive terms. The concept of “normalization” originated in Denmark in the late 1950s. This principle helped convince people that individuals with disabilities belong in our communities. [1]

CURRENTLY

"… ***the public, and many in the medical community, can underestimate the lives of people with disabilities*** (emphasis added)… *People with disabilities worry those judgments will reflect a prejudice that their lives hold less value… Mostly, though, the belief among people with disabilities that they will get lesser treatment is based on something even more concrete – their own harsh experiences in the medical system before the pandemic."* [1]

"Studies have found that women (with disabilities) are less likely to get mammograms and Pap tests. Another study found that those who get breast cancer are less likely to receive standard treatments and, as a result, **are more likely to die.** (emphasis added)" [1]

"(However,) quite often (people with disabilities) have to worry about what kind of care they're going to get, the quality of care, or if someone's even going to give them care." [1]

> "The growing evidence is that disability is not an unavoidable consequence of injury and chronic disease but results in considerable measure, from societal decisions and actions in the public arena as well as in commerce and other private domains."

For the period between 2017 and 2019, about 1 in 6 (17%) children with ages between 3-17 were diagnosed with a developmental disability, as reported by parents.[5] The Centers for Disease Control and Prevention reported in 2018 that 61 million (26%) adults in the U.S. live with a disability. The percentage of adults living with disabilities is highest in the South.[6]

As health care has improved, many of the once acute and fatal conditions have become chronic and manageable problems. These patients have continued to grow in number and seek care from private practitioners and governmental programs.

Our concerns are now quite different than those in the past generation; for example:

"*Community living* – is there housing available that accommodates their disabilities? Is financial help available?

Transportation – Is transportation available? Is it convenient? Who will pay for it?

Education – Is special education available? Will it result in marketable job skills?

Employment – Will employers hire a person with a disability? Is reliable and affordable transportation available?

Health Care – Are medical and dental treatment available in the community? Does the public health department provide care? Is financial assistance available? Is transportation available?[7]

AS TO THE FUTURE

Which are the most important trends and developments that will change the everyday life of people with disabilities?

1. *Becoming disabled will become more "normal."*
2. *Barriers will disappear.*
3. *Jobs will become more responsive to increasing competitive pressure and a rougher market.*
4. *New approaches to inclusion will reform the educational area.*[8]

"… how will U.S. society make the choices that will help define the future of disability? Will the country commit to actions to limit the development and progression of physical and mental impairments in late life, promote good health for children and young adults with early-onset disabilities, and reduce environmental barriers for people with existing impairments?"[9]

"… the growing evidence (is) that disability is not an unavoidable consequence of injury and chronic disease but results in considerable measure, from societal decisions and actions in the public arena as well as in commerce and other private domains. Actions that prevent or reduce rather than create disability include: 1) making products and places more accessible to people with disabilities, 2) eliminating policy disincentives for work, financing equitable access to assistive services and technologies, 3) preparing health care professionals to provide appropriate care to people with disabilities, and 4) investing in research to guide the design of policies and practices that promote independence and participation. **Ultimately, the future of disability in America rests with Americans."** *(emphasis added)*[9]

"Having a disability shapes a person's life, but it is not their total destiny." (Senator Robert Dole, 1999)[10] •

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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.

References

1. State of Alaska: Disability and special education - Disability History Exhibit. Available from: http://dhss.alaska.gov/gcdse/pages/history/html_content_main.aspx Accessed April 4, 2021.

2. Shapiro J. People with disabilities fear pandemic will worsen medical biases Available from: https://www.npr.org/2020/04/15/828906002/people-with-disabilities-fear-pandemic-will-worsen-medical-biases Accessed April 4, 2021.

3. Miles M. Martin Luther and childhood disability in 16th century Germany: What did he write? What did he say? Available from: https://www.independentliving.org/docs7/miles2005b.html Accessed April 26, 2021.

4. Muny CW. Past and present perceptions towards disability: A historical perspective. Available from: https://dsq-sds.org/article/view/3197/3068&sa=U&ved=0ahUKEwjIpcnIlubKAhULaz4KHX_YDy0QFgg0MAc&usg=AFQjCNEWDZ_0jsTk0B8Q2JDebeZ2Ngp2QQ Accessed April 7, 2021.

5. Ryan F. Fear of damaged goods. Available from: https://www.newsstatesman.com/voices/2014/05/two-thirds-us-are-uncomfortable-talking-disable-people-we-need-time-money-and-effort Accessed April 7, 2021.

6. Zablotsky B, et al. Prevalence and trends of developmental disabilities among children in the US: 2009–2017. Pediatrics. 2019; 144(4):e20190811.

7. Centers for Disease Control and Prevention. Disability impacts all of us. Available from: https://www.cdc.gov/media/releases/2018/p0816-disability.html Accessed April 8, 2021.

8. Paul Burtner College of Dentistry. Society's attitude toward people with disabilities: changing attitudes. Available from: https://paul-burtner.dental.ufl.edu/oral-health-care-for-persons-with-disabilities/societys-attitude-towared-people-with-disabilities Accessed April 8, 2021.

9. Diversity MN. People with disability in 2035: how major trends will change their everyday life. Available from: http://en.diversitymine.eu/people-with-disability-in-2035-how-major-trends-will-change-their-everyday-life/ Accessed April 9, 2021.

10. The future of disabilities in America. Available from: https://www.ncbi.nlm.nih.gov/books/NBK11426/ Accessed April 8, 2021.

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EP CELEBRATES ITS 50TH YEAR!

YEARS OF EP MAGAZINE

50 FOR 50

PART I OF II

EP RETROSPECTIVE

"Advocacy means learning, power and knowledge. Advocacy means endurance, learning to be strategic, to recognize that you are not alone and that collaboration effects change. Long-term change does not happen overnight; for me advocacy is a lifelong adventure."

~ Judy Heumann, EP 2021 Advocate Hero

CONGRATULATIONS AND THANK YOU, EP MAGAZINE ADVOCATE HEROES!

50 FOR 50

50 YEARS OF EP • 50 ADVOCATE HEROES • PART I 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.

While 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.*

LAUREN AGORATUS, M.A.

"Having my daughter changed my career path: I became an advocate because I was struggling with both the medical and educational systems that were supposed to be helping our family, and I didn't want other parents to have to go through the same struggles we faced. Getting information makes families feel less helpless and hopeless. Also, parents of children with special needs may not have all the choices they had before and may not like all the choices. But they still have the power to decide what's best for their children."

Lauren Agoratus works as the State Coordinator for Family Voices, housed at SPAN Parent Advocacy Network (www.spanadvocacy.org). She volunteers as New Jersey representative for the Caregiver Action Network for caregivers across the lifespan. Ms. Agoratus says she is privileged to serve locally on the Boards of both NAMI (National Alliance on Mental Illness) Mercer, and the Progressive Center for Independent Living. Statewide, she has served on the SICC (State Interagency Coordinating Council) and SSEAC (State Special Education Advisory Council.)

Currently, she serves on the Council for Children with Disabilities, as well as NJ Immunization Network (AAP NJ), NJ Time to Care Coalition, PerformCare Parent Leader Workgroup, and SERV Behavioral Health. Nationally, she has served as a Family Advisor for Children and Youth with Special Health Care Needs National Research Network, National Quality Forum Pediatric Measures Steering Committee, National Child and Adolescent Health Measure Initiative, and Population Health for Children with Medical Complexity Project.

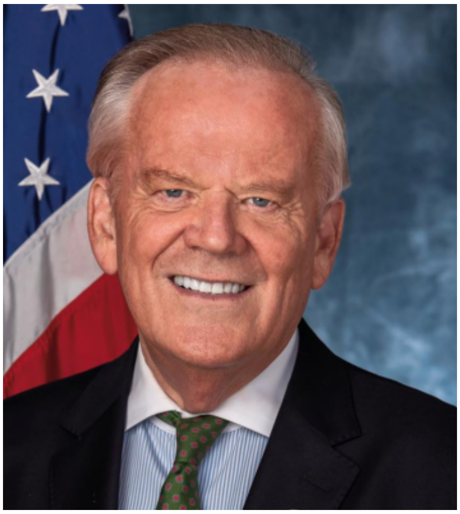
Ms. Agoratus serves on the National Institute of Child Health pediatric priorities panel, Center for Health Care Strategies Advisory Committee on Medicaid and Family Engagement, and the Center for Dignity in Healthcare for People with Disabilities transplant committee. She has done presentations, as well as written articles and blogs for state/national publications, and is a reviewer for the Patient Centered Outcomes Research Institute, National Clearinghouse of Rehabilitation Training Materials, and Johns Hopkins University Press Progress in Community Health Partnerships: Research, Education, and Action.

INFORMATION IS POWER: "Parents of children with special needs may not have all the choices they had before and may not like all the choices. But they still have the power to decide what's best for

All of these experiences have helped Ms. Agoratus get the best information out to empower families and advocate with them for systemic change. She is a parent of a medically-complex young adult.

JAMES (JIM) T. BRETT

"Helping people with disabilities achieve a high quality of life is the most meaningful work I have done in my life. I am so fortunate to be able to take what I have learned over the years, from my family to the State House, the region, and Capitol Hill, and serve as an advocate on a national level. There are countless stories of individual assistance, research programs, and policy initiatives that I have worked to advance. I have seen much progress, but there is so much more we can do. The community needs voices. And I also believe that raising awareness about issues that impact people with disabilities has an even bigger impact on society than we can ever imagine."



RAISING AWARENESS: "I have seen much progress, but there is so much more we can do."

James T. Brett, President and Chief Executive Officer of The New England Council, was appointed by the Council's board of directors in October 1996. The Council, a nationally respected and influential regional organization, established in 1925, is an alliance of schools, hospitals, corporations, and other private organizations throughout New England, working together to promote economic growth and a high quality of life in the region. Mr. Brett has been a leading voice in advocating for public policy issues such as healthcare, education, financial services and energy throughout New England and Washington, D.C. He is co-host of D.C. Dialogue, a monthly public affairs program broadcast on New England Cable News.

Formerly Chairman of the President's Committee for People with Intellectual Disabilities, he currently serves as Chairman of the Governor's Commission on Intellectual Disabilities, and serves as Chairman of Massachusetts Disabled Persons Protection Commission. Before joining the Council, Mr. Brett served for more than 15 years as a member of the Massachusetts House of Representatives. He held a succession of leadership positions, including the chairmanship of two of the most significant committees in the Massachusetts legislature, Banking and the Committee on Taxation.

In 2018, Mr. Brett was awarded with the Michael & Kitty Dukakis Lifetime Achievement Award from the Massachusetts Association for Mental Health. In 2014, he was inducted into Special Olympics of Massachusetts Hall of Fame. Also in 2014, the Disability Law Center bestowed upon him the Edward M. Kennedy Leadership Award. In 2013, The University of Massachusetts Boston established the James T. Brett Chair in Disability and Workforce Development, the nation's only endowed Chair in this area. Mr. Brett is a recipient of 16 honorary degrees.

JEAN CAMPBELL

"My personal journey in rare disease patient advocacy began in the early 1990s at the National Organization for Rare Disorders (NORD), which provided an intense hands-on education about this unique and lesser-known community. Introduction to this community, along with its challenges and triumphs, compelled me to stick around. Now, even as a consultant, I am fortunate to continue to meet and work with resilient people with extraordinary experiences who are friends, mentors, and colleagues. The 30+ years with the rare disease community has been life-changing for me and my family; I am beyond blessed to have embarked on a career path that became a vocation."

ENDURING GRATITUDE: "I am fortunate to continue to meet and work with resilient people with extraordinary experiences who are friends, mentors, and colleagues."

Jean Campbell served two decades with NORD in senior management positions, leading significant expansion of NORD's programs, including the Corporate Council, Restricted Grant Program and the Regional Meet-ups. Currently, JF Campbell Consultants LLC is where Ms. Campbell imparts her patient advocacy and nonprofit governance expertise to industry and patient advocacy organizations. It's all about building responsible and transparent relationships. Often referred to as "everyone's mentor", Ms. Campbell always makes time to speak with individuals from industry and patient advocacy organizations on a wide range of topics.

As a co-founder of the Professional Patient Advocates in Life Sciences (PPALS), Ms. Campbell is committed to meeting the ever-growing needs of the constantly evolving patient advocacy function within industry. She is a member of the Rare Collective and in addition to PPALS, serves on Board of Directors for Erdheim-Chester Disease Global Alliance and Our Odyssey. Somehow, she finds time to serve on MedunikCanada's Advisory Board, EP Magazine's Editorial Board, Sanford CoRDS' External Advisory Board and acts as a judge for EveryLife's Rare Artist Contest. A believer that her accomplishments have always been about connections and collaborations, Ms. Campbell credits surrounding herself with strong mentors like Abbey Meyers, Maria Hardin, Nancy Harris, Estelle Benson, Steve Groft, Rob Tomaino and David LaGreca. She is grateful for her longtime relationship with her colleagues who've been affiliated with EP: Joe Valenzano, Rick Rader, David Hirsch, Esther Schleifer and the beloved, late Max Schleifer.

When seeking some downtime, Ms. Campbell can be found with her two granddaughters, Madeline and Juliette, her daughters, Meredith and Liz, son-in-law Aaron, family, and friends. Rumor has it that she keeps up to date on local events with a special circle of friends at their long running Saturday breakfast gatherings, attends ballroom dance classes, and is an avid movie-goer! Ms. Campbell is forever grateful to Tom, her late husband, who never seemed to mind her crazy life of working with the rare disease community; in fact, he encouraged it.

HENRY (HANK) CHAMBERS, MD

"When we start medical school and advance through our careers as physicians, we are encouraged to be a "triple threat": a great clinician, educator and researcher. As I advanced through my career, it became apparent that one needed to be a "quadruple threat" by adding Advocacy. Those of us who care for children and adults with developmental disabilities are always aware of how underfunded care and research are for our patients.

"I have been fortunate to work with hospitals and professional organizations whose interests align with mine and my patients. In that role, I have had the opportunity to lobby for our patients at a local, state and national level. With the American Academy for Cerebral Palsy and Developmental Medicine and the Reaching for the Stars organization, we were able to meet with Representatives and Senators on Capitol Hill to obtain some funding for research in the field of cerebral palsy. This was a small victory, but energized us to continue working for legislation to increase awareness and ultimately funding for our very underserved population."

Hank Chambers, MD, a pediatric orthopedic surgeon, is currently the Director of the Southern Family Center for Cerebral Palsy Program at Rady Children's Hospital. He is also the Medical Director of the David H. Sutherland MD Motion Analysis Laboratory. Dr. Chambers was the Chief of Staff at Rady Children's Hospital San Diego from 2004 to 2006. He is active nationally in many organizations, including the American Academy of Orthopedic Surgeons, the Pediatric Orthopedic Society of North America, and the American Academy of Pediatrics. He is a Past President of the American Academy for Cerebral Palsy and Developmental Medicine and is also the Past President of PRiSM, a pediatric sports medicine research society which he co-founded. He has published over 120 publications and has authored over 30 book chapters.

FINDING FUNDS: "Those of us who care for people with developmental disabilities are always aware of how underfunded care and research are for our patients."

He has been fortunate to have been the Visiting Professor at over 100 institutions throughout the world, and has been recognized as one of the Top Doctors in San Diego, Best Doctors in America, Top Doctors in the US News and World Report and Who's Who in America and in the World

His wife, Jill, is active in many local and national patient advocacy groups and is a healing touch provider at Rady Children's Hospital. His son, Sean (38), who has cerebral palsy, is currently living independently (with support) in San Diego and his other son, Reid (37) is a pediatric orthopedic surgeon at Nationwide Children's Hospital in Columbus, OH.

STEVEN M. (STEVE) EIDELMAN, MSW, MBA

"My personal journey started in graduate school when I was fortunate to have a one-year placement at the John F. Kennedy Institute for Handicapped Children (now the Kennedy-Krieger Institute) in Baltimore, one of the first University Centers of Excellence. I saw firsthand how our systems all too often disadvantage children with disabilities and their families, making it harder for them to thrive. It stirred my sense of social justice that has kept me moving forward for over 40 years.

"Advocacy for people with disabilities has greatly improved the services and supports that are available. As people with disabilities continue to take their rightful places in our communities, advocacy is as important as it ever was; maybe more so."

Steven Eidelman is The H. Rodney Sharp Professor of Human Services Policy and Leadership in the Department of Human Development and Family Sciences and a Professor in the Biden School of Public Policy and Administration at The University of Delaware. He is also the Faculty Director and co-founder of the National Leadership Consortium on Developmental Disabilities, a program designed to enhance the effectiveness of the next generation of professional leaders in the field of delivery of services and supports in the community. He has experienced, first-hand, the power of advocacy by families and, increasingly, by people with disabilities themselves. As a state director of developmental disabilities, he oversaw the implementation of early intervention services for children birth to three years as an entitlement program. He was the official in charge when the infamous Pennhurst State School was closed.

A MORE JUST SOCIETY: "As people with disabilities take their rightful places in our communities, advocacy is as important as it ever was; maybe more so."

Prof. Eidelman's professional interests include community-based and inclusive supports to people with intellectual disabilities and their families, development of professional leadership in the intellectual/developmental disabilities field, and research on international policy and practice particularly in Eastern Europe and the Former Soviet Union. He also teaches undergraduate students about public policy as it impacts children and their families, as well as graduate students focused on building more competent and engaged leaders. In 2015, Prof. Eidelman was selected, for a second time, to receive the American Association on Intellectual and Developmental Disabilities' Leadership Award; Prof. Eidelman is only the second two-time Leadership Award recipient in over 100 years.

Prof. Eidelman was an Executive Director of The Arc of the United States. He is a Past President of the American Association on Intellectual and Developmental Disabilities. In addition, he has been an Expert Witness – Federal Court Case – *Ligas v. Miram,* Illinois and provided Expert Opinion for Birchut, Civil Rights of People with Disabilities in Israel. He also serves as Senior Advisor to the Chairman of Special Olympics International and as the Executive Director of the Joseph P. Kennedy, Jr. Foundation where he works on issues related to improving the lives of people with intellectual disabilities and their families.

TEMPLE GRANDIN, PH.D.

"We need to look at what a child can do instead of always concentrating on the things they cannot do. Build on a child's area of strength.

"To determine what your child is good at, they need to be exposed to many different things. My mother always encouraged my ability in art. She always urged me to paint and draw a variety of different subjects."

Temple Grandin is a professor of animal science at Colorado State University. When she was two-and-a-half years old, she had no speech and all the symptoms of severe autism. Early intensive speech therapy enabled her to speak by age four. Her mother always encouraged her interest in art and urged her to draw many different things. Good teachers and mentors were essential for Dr. Grandin's success. Her high school science teacher challenged her with interesting projects where she had to figure out how to make things work. When studying in school became a pathway to becoming a scientist, she was motivated to study.

BUILDING ON STRENGTHS: "To determine what your child is good at, they need to be exposed to many different things."

Dr. Grandin earned her B.A. in human psychology from Franklin Pierce College, and her M.S. in animal science from Arizona State University. Her doctoral degree in animal science is from the University of Illinois at Urbana-Champaign.

Dr. Grandin was inducted into The National Women's Hall of Fame and The Academy of Arts and Sciences. Facilities she has designed handle over half the cattle in the U.S. Some of her most important books are New York Times Bestseller *Animals in Translation, Thinking in Pictures, The Autistic Brain,* and *The Way I See It.* An HBO movie titled *Temple Grandin* was made about her life.

JUDITH E. (JUDY) HEUMANN

"I have spent much of my life advocating with and on behalf of disabled children and adults. Having had my disability when I was 18 months old, I learned from my parents that unless we were strong advocates, the biases, low expectations and ultimate discrimination would result in limited opportunities.

"Advocacy means learning, power and knowledge. Advocacy means endurance, learning to be strategic, to recognize that you are not alone and that collaboration effects change. Long-term change does not happen overnight; for me advocacy is a lifelong adventure."

Judith (Judy) Heumann is a lifelong advocate for the rights of people with disabilities. She contracted polio in 1949 in Brooklyn, New York and began to use a wheelchair for her mobility. She was denied the right to attend school because she was considered a "fire hazard" at the age of five. Her parents played a strong role in fighting for her rights as a child, but Ms. Heumann soon determined that she, working in collaboration with other disabled people, had to play an advocacy role due to continuous discrimination.

Ms. Heumann has been instrumental in the development and implementation of legislation, such as Section 504, the Individuals with Education Act, the Americans with Disabilities Act, the Rehabilitation Act, and the UN Convention on the Rights of Persons with Disabilities which have been advancing the inclusion of disabled people in the US and around the world and fighting to end discrimination against all those with disabilities. During his presidency, President Obama appointed Ms. Heumann as the first Special Advisor for International Disability Rights at the U.S. Department of State, where she served from 2010-2017. She also served as the World Bank's first Adviser on Disability and Development from 2002 to 2006.

LIFE LESSONS: "I learned from my parents that unless we were strong advocates, the biases, low expectations and ultimate discrimination would result in limited opportunities."

Ms. Heumann is an internationally-recognized leader in the disability rights community. Her memoir which she co-authored is titled *Being Heumann: An Unrepentant Memoir of a Disability Rights Activist.* She is featured in *Crip Camp: A Disability Revolution,* a 2020 American award-winning documentary film. She also produces a podcast called The Heumann Perspective. She has been featured in numerous documentaries, including on the history of the disability rights movement, *Lives Worth Living* and *The Power of 504*. As Senior Fellow at the Ford Foundation (2017-2019), she wrote *Road Map for Inclusion: Changing the Face of Disability in Media.* She currently serves on a number of non-profit boards, including the American Association of People with Disabilities and the Disability Rights Education and Defense Fund.

Ms. Heumann has received numerous awards, including being the first recipient of the Henry B. Betts Award in recognition of efforts to significantly improve the quality of life for people with disabilities and the Max Starkloff Lifetime Achievement Award from the National Council on Independent Living. She has been awarded numerous honorary doctorates. She graduated from Long Island University in Brooklyn, NY in 1969 and received her Master's in Public Health from the University of California at Berkeley in 1975.

TEMPLE GRANDIN PHOTO BY ROSALIE WINARD

GENERAL JAMES L. JONES, USMC (RET.)

"As parents of a severely disabled young lady who is approaching the age of 50, we have spent much of our time counting the blessings that our daughter, Jennifer, has brought to our family. She has taught us many things, but her gift of compassion to us and to her three brothers and their families stands out from all others.

"As a Marine, it was my privilege to advocate for assistance to Marine families who had children with disabilities, so that they wouldn't have to choose between the welfare of their families and their careers. We were also able to help Marines who sustained disabilities while on active duty so that they could be retained rather than be separated. We accomplished this through a much-needed retraining program which gave new hope to our injured Marines and contributed greatly to our readiness."

STRATEGIC FORESIGHT: **"It was my privilege to advocate for assistance to Marine families who had children with disabilities, so that they wouldn't have to choose between the welfare of their families and their careers."**

"General James L. Jones is the father of three sons and one daughter with a profound disability. Together with his wife, Diane, the couple experienced firsthand the daunting, challenging task of parenting a child with special needs... Parenting a child with special needs and three other children gives clearer meaning to the phrase Exceptional Parent, and the General and Mrs. Jones have certainly earned that distinction. Overlay this with the duties and responsibilities of life in the military, with frequent deployments, separations and relocations, and you begin to appreciate the extraordinary challenges faced by our men and women in the military, many of whom are parents of special needs children. With a vested interest in programs for persons with disabilities, General Jones and Diane have been champions for the cause of special needs for Marines and other service members and their families...As First Lady of the Marine Corps, Diane Jones was especially concerned about Marines whose family members were part of the Exceptional Family Member Program. She helped to create the Marine Corps Family Readiness Committee as a voice and advocate for all the family and volunteer programs. She fostered a Committee for Persons with Disabilities comprised of family, base and community representatives on every major Marine Corps base." *(Source: "Meet the Joneses",* EP Magazine, *July 2002)*

General Jones was appointed by President Barack Obama as National Security Advisor to the President on January 20, 2009. During his tenure in the White House, General Jones served as a trusted Presidential advisor, represented the President as an envoy to American allies and partners, provided steady leadership during times of conflict, and oversaw an expansion of responsibilities of the National Security Council to include cyber security, homeland security, and strategic foresight.

General Jones came to the White House from the private sector, where he served as the President and CEO of the U.S. Chamber of Commerce's Institute for 21st Century Energy. General Jones retired from the U.S. Marine Corps in February 2007 after a distinguished 40-year career. From July 1999 to January 2003, General Jones served as the 32nd Commandant of the United States Marine Corps. He served as Commander of all NATO forces.

Upon leaving the White House in 2010, General Jones founded Jones Group International, assisting clients in matters of energy security, national and international security, market access and trade promotion, and strategic leadership. General Jones graduated from the Georgetown University School of Foreign Service.

STEVEN P. (STEVE) PERLMAN, DDS, MSCD, DHL

"I've been privileged to have devoted much of my career to the education and training of fellow healthcare professionals in the treatment of children and adults with intellectual and physical disabilities. For over 45 years, I have heard countless stories and experiences shared by my patients, their families and caregivers of how they were denied equitable healthcare. Having the opportunity to advocate for changing the beliefs, attitudes and knowledge of students and professionals has been a blessing I have been fortunate to experience."

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.

DEVOTED TO CHANGE: **"Having the opportunity to advocate for changing the beliefs, attitudes and knowledge of students and professionals has been a blessing."**

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.

JO ANN SIMONS

"Advocacy means standing up against injustice and exclusion wherever it occurs. It means joining with other marginalized groups to make sure that people with disabilities are included in all social justice initiatives. It means that making sure that whenever the word 'inclusion' is used, it includes people with disabilities."

Jo Ann Simons, MSW, is the Chief Executive Officer of The Northeast Arc, a not-for-profit organization that helps children and adults with disabilities become full participants in the community. Ms. Simons came to the Northeast Arc from Cardinal Cushing Centers where she served as President & CEO since 2008. This was a return to the Northeast Arc for her who, early in her career, served as the organization's Director of the Community Division and Director of Family Educational Services. During this time, she started the first Family Support Program in the state and one of the first in the country.

STANDING UP: "Whenever the word 'inclusion' is used, it includes people with disabilities."

Ms. Simons has had a successful career working with a variety of agencies focused on serving people with developmental disabilities. After her first stint at the Northeast Arc, she went on to serve as the Director of Policy for the Massachusetts Department of Developmental Services, The Deputy Facility Director of the Fernald Development Center, and Executive Director of the Arc of East Middlesex, before leading Cardinal Cushing Centers in their master plan to create intergenerational communities on both the Hanover and Braintree campuses. She is a past chair of the National Down Syndrome Society, past president of the National Down Syndrome Congress, and a consultant to Special Olympics. She is the author of the *Down Syndrome Transition Handbook*, and *Footprints for the Future.* She also contributed chapters to the books, *Babies with Down Syndrome* and *Treating the Dental Patient with a Developmental Disorder.*

Ms. Simons has two adult children: Jonathan, who has Down syndrome and lives independently in his own home and has a life filled with meaningful paid work, important volunteer activities, and many leisure pursuits. Emily is a litigator.

Ms. Simons received her Bachelor of Arts degree in Urban Studies from Wheaton College and a Masters of Social Work degree in Policy, Planning, and Community Organization from the University of Connecticut.

TIMOTHY P. (TIM) SHRIVER, PH.D.

"Advocacy for people with disabilities has evolved from a niche cause to a global movement where people hold each other accountable. Just ten years ago, it was common to hear the R-word used as a slur. In the past 30 years, the Americans with Disabilities Act has leveled the playing field for people of all ages across the country. As we celebrate the 100th birthday of my mother and the founder of Special Olympics, Eunice Kennedy Shriver, it is more clear than ever that inclusion for people with disabilities matters to everyone. Students, teachers, employers, policymakers, and people in communities across the US are demanding inclusion, proving that one idea, one grain of sand, can move mountains."

LEVELING THE PLAYING FIELD : "Students, teachers, employers, policymakers, and people in communities across the US are demanding inclusion."

Timothy P. Shriver has served as the Chairman of Special Olympics International since 1996. He currently serves alongside more than 6-million Special Olympics athletes and their families in over 195 countries around the world. During Dr. Shriver's time as Chairman, Special Olympics has developed proven programming for all aspects of a Special Olympics athlete's life: leadership, health, education, and family support. His commitment to inclusion is evident by Special Olympics athletes serving on the International Board of Directors, hundreds of thousands of health professionals trained in adaptive healthcare protocols, partnerships with organizations like the World Health Organization, United Nations, and the Unified Champion Schools Program creating a Unified Generation in which all people are included and accepted regardless of intellectual differences.

Dr. Shriver drove the largest expansion of Special Olympics, growing the movement from one million athletes to over 6-million athletes and unified partners that are leading the Inclusion Revolution around the world. He has harnessed the power of Hollywood to challenge unconscious bias and share stories of inspiration, co-producing DreamWorks Studios' 1997 release, *Amistad,* and Disney Studios' 2000 release, *The Loretta Claiborne Story*. He is Executive Producer of *The Ringer,* a Farrelly Brothers film.

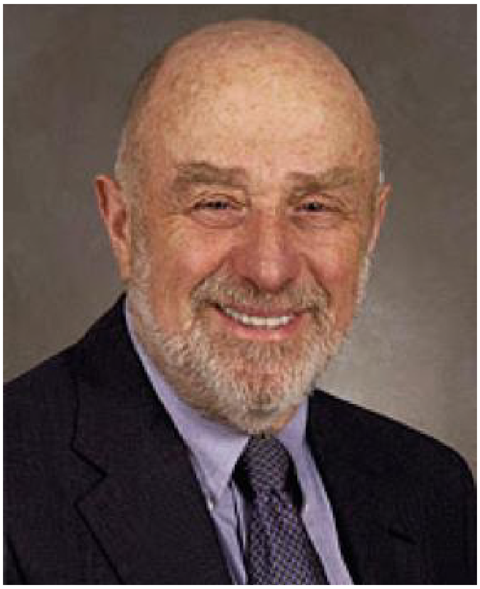
Before joining Special Olympics, Dr. Shriver co-founded and currently chairs the Collaborative for Academic, Social, and Emotional Learning (CASEL). He is a member of the editorial board of the Disability and Health Journal. Shriver is the Co-Founder of UNITE, a member of the Council on Foreign Relations, President of the Joseph P. Kennedy Jr. Foundation, UNESCO Chair for "Transforming the Lives of People with Disabilities, their Families and Communities, Through Physical Education, Sport, Recreation and Fitness" at the Institute of Technology, Tralee, Ireland, and Co-Founder of Lovin' Scoopful Ice Cream Company.

Dr. Shriver earned his undergraduate degree from Yale University, a master's degree in Religion and Religious Education from Catholic University, and a Doctorate in Education from the University of Connecticut. He and his wife Linda Potter live in the Maryland suburbs of Washington, DC and they are the proud parents of five adult children and grandparents of three grandchildren.

H. BARRY WALDMAN, DDS, MPH, PHD

"There have been more than 60 years of writing and advocating for the healthcare of individuals with disabilities, together with providing the needed services and instituting the requirements for all dental and dental hygiene schools in the U.S. to prepare the next generations of students with the needed training to care for individuals with disabilities. They have filled my life with joys and satisfaction (and yes, hugs too) of being part of the changes that now recognize that the young and not so young with disabilities live in our world and we can help them fulfill their lives."

Dr. H. Barry Waldman is a State University of New York Distinguished Teaching Professor at the School of Dental Medicine of Stony Brook University. Early in his career, he taught at Western Reserve University and directed programs to bring dental services to homebound patients in the metropolitan Cleveland Ohio area. For more than 50 years, he has taught more than 10,000 students at Stony Brook University in the Departments of Sociology, Nursing, Medicine, Health Technology and related health and social programs. He has been active for more than 60 years in a wide range of dental and general medical fields; and continues on in his career.

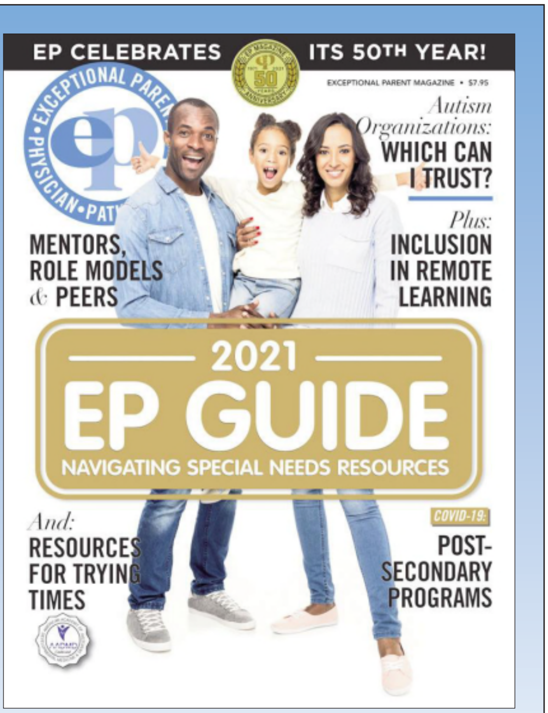


PREPARING THE NEXT GENERATION: "The young and not so young with disabilities live in our world and we can help them fulfill their lives."

Dr. Waldman received numerous government and agencies for individuals with disabilities awards to enhance his formal training in the care of children and adults with cerebral palsy and other disabilities. His training in public health, medical care organization, and related fields led to Board Certification in Public Health Dentistry and a doctoral degree in Medical Care Organization.

Since the mid-60s, Dr. Waldman has published 1,200 articles and book chapters, including more than 400 items related to the care of individuals with disabilities in regional, national and international publications.

High points in his career include: his leading role to establish dental and dental hygiene school accreditation requirements to provide all students with experiences in the care of individuals with disabilities; and expand the American Dental Association Code of Ethics to include the care of individuals with disabilities. •



GOLDEN ANNIVERSARY
50 YEARS OF EP
1971 – 2021

TOWARDS JUSTICE: Students in an integrated classroom in Fort Myer, Va., the year of Brown v. Board of Education. The Supreme Court had knocked down the foundation of school segregation based upon race, the "separate but equal" doctrine.

PHOTO COURTESY CORBIS

[PART ONE OF TWO]

A BRIEF HISTORY OF SPECIAL EDUCATION

MILESTONES IN THE FIRST 50 YEARS

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

Most people would consider the struggle for disability rights and inclusion to have begun in the early 1970's with the PARC Consent Decree *and the passage of P.L. 94-142, The Education for Handicapped Children Act. However, the disability rights movement and the creation of special education laws owe a debt of gratitude to Thurgood Marshall who argued in 1954 before the United States Supreme Court in the* Brown vs. The Board of Topeka, Kansas.

In this landmark decision, the Supreme Court knocked down the "separate but equal" doctrine, which was the foundation of school segregation based upon race. Disability rights advocates used this premise to argue that disabled students were being excluded from education or were served separately in substandard conditions. Estimates were that over 7 million students with disabilities were excluded from public education.

Beyond dismissing the doctrine of "separate but equal" another impact of *Brown vs. The Board of Topeka* decision was that social movements began turning to the courts for remedy. The Brown case was on the behalf of a "class" of people, having widespread impact for students based on race. In the early 70s there were two seminal class action court cases where states were challenged for not providing an education to students who were disabled, arguing that students with disabilities had the same rights as students without disabilities, and that because of the Brown case, all non-disabled students had the right to an education. The *PARC (Pennsylvania Association for Retarded Citizens) v. the Commonwealth of Pennsylvania* ended in a settlement agreement in 1972. The PARC Consent Decree stated that the state of Pennsylvania had to provide a free public education for all students with intellectual disabilities and included procedure protections. Similarly, the Mills v. Board of Education was against the District of Columbia in 1972. The Mills case extended the right to education to all students with disabilities in the District of Columbia, including students who were being denied an education due to expulsion and suspension as disciplinary measures (Yell et al., 2011).

SUMMER OF LOVE: Camp Jened was the subject of *Crip Camp*, the documentary that argues that the camp helped feed the sense of community that led into the American disability rights movement in the 1970s.

Across the country other class action lawsuits were happening based on the need for change in the educational systems. As this was occurring, the Vocational Rehabilitation Act of 1973 and specifically Section 504 of the Act, became the first piece of federal legislation that made it illegal for public institutions which received federal funds to discriminate against individuals on the basis of disability. Initially, the law was used to provide physical access to buildings for those individuals with mobility issues. The struggle to obtain those rights is beautifully captured in therecently-Oscar nominated documentary film, *Crip Camp*. Those same advocates pushed to have the rights of individuals with disabilities expanded to include private entities with the passage of the Americans with Disabilities Act of 1990. Although initially aimed at protecting the rights of individuals with physical disabilities and providing physical access, the protections were expanded beyond physical access and physical disabilities.

> *"Another impact of Brown vs. The Board of Topeka decision was that social movements began turning to the courts for remedy. The Brown case was on the behalf of a 'class' of people, having widespread impact for students based on race."*

Shortly after the Vocational Rehabilitation Act was passed, federal legislation was passed that mandated and protected the rights of all children with disabilities to have a free public education. The *PARC* and *Mills* cases provided the blueprint for Public Law 94-142: The Education for All Handicapped Children Act of 1975 (EHA). It is commonly reported that there are six major principles of the EHA (now called IDEA), however, what is included in the list varies; here we are reporting seven major principles that are all still a part of today's law:

1. All students have a right to a free and public education, known as F.A.P.E.
2. All students have a right to be educated in the Least Restrictive Environment, L.R.E.
3. All students have a right to an Individual Education Program
4. Non-discriminatory assessment and evaluation
5. Parent involvement
6. Due process procedural safeguards
7. Zero-reject

Once legislation has passed, implementation begins which leads to defining the terms and standards of the legislation. As new laws are implemented, the courts, through litigation, are used to provide guidance in following the mandates. Some court decisions have limited reach, while others cross geographic regions, all dependent on how high in the system the case is heard. Federal laws then become "reauthorized", with changes based, in part, on the findings of the courts. Naturally, after the EHA was passed, there were key court cases that further defined the mandates. In 1982 the *Hendrick Hudson Dist. Bd. Of Ed. V. Rowley* was the first EHA case heard by the Supreme Court. Amy Rowley, a deaf student, and her parents requested a sign-language interpreter for Amy but were denied. The lower court established that each child should be given the supports needed to reach their fullest potential. However, the Supreme Court overruled, stating that that an *appropriate education* was provided if the IEP was "reasonably calculated to confer educational benefit" (Yell et al., 2011). Because Amy was doing well aca-

PHOTO COURTESY PATTI SMOLIAN/HIGHER GROUND PRODUCTIONS

demically, she was denied an interpreter. Because the term "educationally benefit" did not specify a standard for adequate educational benefit, future cases applied different standards in deciding whether the provision of FAPE was provided based on educational benefit (Yell & Bateman, 2020).

In 1984, there was another key court case focused on related services in relation to the provision of FAPE. *Irving Independent School District v. Tatro* stated that health care services that can be provided by a nurse or other trained professional must be provided to the student as a related service if they are necessary to enable the student to receive FAPE; medical services required to be delivered by a physician were not consider a related service. Amber Tatro was an eight-year-old with spina bifida who required clean intermittent catheterization (CIC) during the school day. The school district considered this a medical service and therefore they were not required to include the use of a CIC in her IEP. One of the compelling arguments that this was a related service and not a medical service was that Ambers family members were, after a short training, qualified to perform the procedure, and it was anticipated that Amber herself would soon be able to perform the procedure.

WALKING TALL: Amber Tatro's 1984 victory over the Irving, Texas, Independent School District in the U.S. Supreme Court ensured disabled students the right to public education.

PHOTO COURTESY LIBRARY OF CONGRESS

In 1986, there was a reauthorization of the EHA; the significance of this reauthorization is that it expanded who was covered to include early intervention services beginning at birth through the age of two years old; previously, the EHA covered young children beginning at the age of three. Additionally, it was established that children receiving those services were required to have an Individualized Family Service Plan, a provision that expanded the requirement of an IEP to include services for the family. Also of importance, in that same year, congress passed The Handicapped Children's Protection Act that authorized courts to award attorney's fees and other expenses that parents or guardians incurred because of pursuing administrative or civil actions under the EHA act of 1975, strengthening the provision of due process procedural safeguards (Florian & West, 1989).

There were several notable court cases that occurred before the next reauthorization in 1990. In 1988 the *Honig v. Doe* case addressed the expulsion of students with behavioral challenges. The resulting ruling was that schools could not expel a student because of a behavior related to their disability and that suspensions that were over 10 consecutive days in length were considered a change of placement, requiring the IEP team to reconvene. Expulsion or a suspension that lasted longer than 10 days without a change of placement would be considered a denial of FAPE. This case also established that the student would stay in the current placement (stay-put provision) during any administrative or judicial hearings and procedures (Yell et al., 2011).

> *"The result of Honig v. Doe was that schools could not expel a student because of a behavior related to their disability."*

In 1989, in *Timothy W. v. Rochester*, a court found that a student was wrongly being denied FAPE because the school district considered him too disabled to receive benefit from an education. The ruling in this court reaffirmed the notion that all students had a right to FAPE, regardless of the severity of their disability, supporting the zero reject provision of EHA (Baumgart & Giangreco, 1996). Another case of significance provided direct guidance to the LRE mandate by implementing a two-pronged test to determine if a student could be moved to a more restrictive environment. In Daniel RR v. State Board of Education (1989), the court applied a two-pronged test, recognizing the difficulty in determining what the *least restrictive environment* is for the student to receive an *appropriate education (FAPE)*. In this case, the fundament question was *when it is okay to remove a student from an inclusive classroom to a self-contained classroom.* The court ascertained that the IEP team must first determine if, with the use of supplemental aids and services, the child can receive an appropriate education in the general education classroom (Marx et al., 2014; Yell & Drasgow, 1999). Significant to this test is the consideration of non-academic benefit. Previously in Rowley it was established that academic benefit was a determination in the appropriateness of an IEP; this case highlighted also the non-academic benefits, such as social benefit. Another consideration was the impact on the education of the non-disabled students in the classroom, giving the school district the leeway to remove a student if they are considered disruptive to the education of other students. The second prong of the test focused on other opportunities to be with non-disabled peers. If the student could not be satisfactorily educated in the academic classroom beside their non-disabled peers, the school must still consider including the student to the maximum extent possible. This case made clear that the intent of the EHA was for students with disabilities to be educated as much as possible alongside their non-disabled peers, and that education included non-academic classroom opportunities as well as lunch and recess (Martin et al., 1996; Marx et al., 2014; Yell & Drasgow, 1999).

INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA)

There were several major changes to the EHA in the reauthorization of 1990; one of those was the name of the law itself. In 1990, the Education for All Handicapped Children Act was renamed to the *Individuals with Disabilities Education Act* (IDEA), emphasizing a change to "people-first" language as well as using the word disabilities in place of handicapped. Also significant was the mandate a transition plan be provided to all students with an IEP beginning at the age of 16. Additionally, this reauthorization added two distinct categories of disabilities to be covered under the law: Traumatic Brain Injury (TBI) and autism. Assistive technology, for the first time, was a part of the law, adding both assistive technology devices and services (Yell et al., 2011).

After the 1990 reauthorization, there were two more court cases that applied "tests" or a process to determine placement in the least restrictive environment. It was an exciting time for advocates of inclusive education because these cases were occurring at the same time in circuit courts on the East and West coasts. Although in *Daniel RR* a "test" was established, it did not need to be applied in courts across the country, which is why it is important to understand how courts impact legislation. When there are multiple cases across different geographic regions that have similar findings, it is not unusual to see the impact of those findings in the legislation. Courts have not been consistent in their rulings for inclusive education, thus utility of using these pronged tests. The *Oberti v. Board of Education of the Borough of Clementon School District* (1993) introduced a three-prong test of LRE. The court determined these factors were relevant in considering the least restrictive environment for an appropriate education:

1. whether the school made "reasonable effort" in including the student in the general education classroom;
2. comparison of the educational benefits of being included in the general education classroom with supplemental aids and services to the benefits of being educated in the special education classroom; and,
3. the impact of the inclusion of the student on their non-disabled peers (Bradley & Wintermann, 2014; Martin et al., 1996; Marx et al., 2014).

The findings of the court were that the school district had not made reasonable effort to include Rafael, a kindergarten student, in part because they had not applied the same strategies and techniques while he was in the general education classroom that were deemed successful in the special education classroom. This further supported the findings of the *Daniel RR* case where it must be first determined that with the use of supplemental aids and services the student will not receive educational benefit before removing the student from the classroom.

MOVE TO INCLUDE: President Clinton signed the IDEA reauthorized legislation in 1997. Several of the changes in the act were directly designed to improve the inclusive opportunities given to students with disabilities through the provision of the IEP.

PHOTO COURTESY WIKIPEDIA

While the *Oberti* case was happening on the East coast, on the West coast the *Sacramento City School District v. Rachel H.* case was occurring. When Rachel Holland was in kindergarten, her parents requested that she be placed in the general education classroom full time; the district contended that Rachel would be best educated in the special education classroom for academic subjects and could be in the general education classroom for non-academic times, requiring Rachel to move back and forth between the classrooms. Similar to the *Oberti* and *Daniel RR* cases, there was a pronged test; this court applied four considerations. The courts considered both the academic and nonacademic benefits, the effects on inclusion on non-disabled students and the teacher; and in the cost of including Rachel (Bradley & Wintermann, 2014; Martin et al., 1996; Marx et al., 2014). The courts found that Rachel would derive more benefit both academically and non-academically in the general education classroom without distracting the other students with the assistance of a part-time aide. Furthermore, the court found that the cost of including Rachel was overestimated by the district and that although it could be a consideration, costs were not a factor that would prohibit Rachel from being included. In both the *Oberti* and *Holland* cases, the court placed the burden of proof on the School Districts, which was seen as a significant win by educational advocates. The outcomes of these cases were celebrated by advocates of inclusion across the country.

The reauthorization in 1997 had many significant implications, and not surprisingly strengthened the focus on inclusive education, although the terms inclusive or inclusion are not in the law itself. Several of the changes were directly designed to improve the inclusive opportunities given to students with disabilities through the provision of the IEP (Wolfe & Harriott, 1998). The composition of the IEP team was addressed by adding the stipulation that at least one general education teacher be involved if the student is expected to be in the general education environment. Added to the existing statement of present levels was the requirement of a statement describing how the student's disability affects his or her involvement and progress in the general education curriculum. Also added was the requirement to justify the extent to which the student will not participate in general education classes and curriculum. The inclusion of all students in state accountability measures were required, even students with “the most significant cognitive disabilities” (Ryndak et al., 2014). This reauthorization made even clearer the preference for inclusive education and involvement in the general education curriculum.

Another area that had a significant focus was that of behavior supports and discipline (Wolfe & Harriott, 1998). There was a focus on providing behavioral supports and a functional behavioral assessment. Before disciplinary action can be taken, or within 10 days, the team must also conduct a manifestation determination to understand whether the behavior that the student is being disciplined for was a manifestation of their disability, and part of the hearing was a review of what assessments and supports were being provided. Transition services was again addressed in this reauthorization lowering the age requirement for a transition statement from 16 to 14 years old. Details of the transition statement were expanded to include that the IEP should be related to the student’s specific course of study, and transition services were defined. When the student reaches the age of 16, those services must be identified, as well as the providers of those services, including interagency responsibilities and linkages.

> *“The Weast decision reversed the burden of proof, meaning it was incumbent upon to the families to prove the IEP was insufficient and not meeting the student’s goals.”*

The next reauthorization of 2004 did not have as many significant changes as the previous one. Although the name was officially changed to the Individuals with Disabilities Education Improvement Act of 2004 (IDEIA), IDEA is still the acronym most used. The changes of this reauthorization are characterized by the alignment with No Child Left Behind Act of 2001 (NCLB), focusing on accountability (Turnbull, 2005). The requirement that special educators be highly qualified was added to IDEIA, along with the provision of evidenced-based practices, both following the lead of NCLB.

One of the little-known outcomes of the re-authorization of IDEA in 2004 occurred during the public commentary period before IDEA. The U.S. Department of Education was responding to advocates’ calls to include language that explicitly allowed school districts to pay for transition services, including community-based and college-based transition programs. The U.S. DOE responded by stating that IEP teams have always had the ability to pay for community-based or college-based transition programs under Part B of IDEA. In fact, the exact language can be found in 34 CFR Parts 300 and 301 Assistance to States for the Education of Children with Disabilities and Preschool Grants for Children with Disabilities: Final Rule, on page 46,668.

The *Schaffer vs. Weast* U.S. Supreme Court decision in 2005 dealt a blow to special education advocates and families. Prior to this decision, when there was a dispute between a family and a school district, the burden of proof was laid upon the school district to demonstrate that the student’s Individual Education Plan (IEP) met the student’s goals. If the school district lost the case, they were responsible for the legal fees of the family. The Weast decision reversed the burden of proof, meaning it was incumbent upon to the families to prove the IEP was insufficient and not meeting the student’s goals. School districts which usually have attorneys on retainer, if not on staff, went from losing the majority of disputes to winning more disputes, especially if families were not represented by legal counsel. •

**A Brief History of Special Education: Milestones in the First 50 Years (Part II) will focus on special education and the transition aged years. It will be published in* EP Magazine*’s July 2021 issue.*

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References

20 Code of Federal Regulations (CFR) Parts, 676, 677, and 678. Department of Labor. Employment and Training Administration.

34 CFR Parts 300 and 301 Assistance to States for the Education of Children With Disabilities and Preschool Grants for Children With Disabilities; Final Rule

34 Code of Federal Regulations (CFR) Parts 361 and 463. Department of Education. Workforce Innovation and Opportunity, Joint Rule for Unified and Combined State Plans, Performance Accountability, the One-Stop System Joint Provisions; Final Rule

34 CFR Parts 361, 363, and 397 RIN 1820-AB70 [Docket ID ED-2015-OSERS-OOO1] State Vocational Rehabilitation Services program; State Supported Employment Services program; Limitations on Use of Subminimum Wage https://s3.amazonaws.com/public-inspection.federalregister.gov/2015-05538.pdf

Baumgart, D., & Giangreco, M. (1996). Key lessons learned about inclusion. In D. Lehr & F. Brown (Eds.), Persons who challenge the system: Persons with profound disabilities (pp. 79-97). Brookes Publishing.

Board of Education v. Rowley, 458 U.S. 176 (1982).

Bradley, L. & Winterman, K. G. (2014). Overview of the history and legal perspectives of Special Education. In K. G. Wintermann & C. E. Rosas (Eds.). The IEP checklist: Your guide to creating meaningful and compliant IEPs. Brookes Publishing.

Brown v. Board of Education, 47 U.S. 483 (1954).

Daniel RR v. State Board of Education, 874 F. 2d 1036 (5th Cir. 1989).

Dracut v. Bureau of Special Education Appeals, 737 F. Supp. 2d 35 (D. Mass. 2010).

Education for All Handicapped Children Act of 1975, 20 U.S.C. § 1401 et seq.

Florian, L. D. & West, J. (1989). Congress affirms the rights of children with handicaps. Teaching Exceptional Children, 21(3), 4-7.

Higher Education Opportunities Act of 2008. (P.L. 110 -315).

Individuals with Disabilities Education Act of 1990, 20 U.S.C. § 1401 et seq.

Individuals with Disabilities Education Act (1997). U.S.C. 20. Part A & Part B. §1400, §1401, §1412, §1414, and §1415.

Individuals with Disabilities Education Act of 1990, 20 U.S.C. § 1401 et seq.

Lehr, D. (2020). Placement of students with severe disabilities who have complex health care needs in general education classes. Research and Practice for Persons with Severe Disabilities, 45(1), 39-44.

Martin, E.W., Martin, R. & Terman, D.L. (1996). The legislative and litigation history of special education. Special Education for Children with Disabilities, 6(1), 25-39.

Marx, T. A., Hart., L., Nelson, L., Love J., Baxter, C. M., Gartin, B., & Whitby, P. J. S. (2014). Guiding IEP teams on meeting the least restrictive mandate. Intervention in School and Clinic, 50(1), 45-50.

Oberti v. Board of Education of Borough of Clementon School District, 995 F.2d 1204 (3rd Cir. 1993).

Ryndak, D. L., Taub, D., Jorgensen, C. M., Gonsier-Gerdin, J., Arndt, K., Sauer, J., Ruppar, A. L., Morningstar, M. E., & Allcock, H. (2014). Policy and the impact on placement, involvement, and progress in general education: Critical issues that require rectification. Research and Practice for Persons with Severe Disabilities, 39(1), 65-74.

The Workforce Innovation and Opportunity Act (WIOA) (H.R. 803).

Timothy W. v. Rochester, New Hampshire, School District, 875 f.2d 954 (1st Cir. 1989).

Turnbull, H. R. (2005). Individuals with Disabilities Education Act Reauthorization: Accountability and personal responsibility. Remedial and Special Education, 26(6), 320-326.

Turnbull, H. R., Shogren, K. A., & Turnbull, A. P. (2011). Evolution of the parent movement: Past, present, and future. In J.M. Kauffman & D.P. Hallahan (Eds.), Handbook of special education (pp. 639–653). Routledge.

Yell, M. L., & Drasgow, E. (1999). A legal analysis of inclusion. Preventing School Failure, 43(3), 118-123.

Yell, M. L., Katsiyannis, A., & Bradley, M. R. (2011). The Individual with Disabilities Education Act: The evolution of special education law. In J. M. Kauffman & D. P. Hallahan (Eds.), Handbook of Special Education (pp. 61-76). Routledge.

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GOLDEN ANNIVERSARY
50 YEARS OF EP
1971 — 2021

FIGHTING ON THE FRONTLINES

THROUGH THE YEARS FOR THE RARE DISEASES COMMUNITY

BY KAREN L. BALL

I was introduced into the world of rare diseases on October 11, 1986. My daughter was born with a large Port Wine Birthmark on her face and diagnosed with Sturge-Weber syndrome (SWS). She had her first eye surgery when she was one week old due to glaucoma, and her first seizure at one year old.

Ever since that infamous day and the ensuing 34 years of medical challenges, surgeries, and the associated financial stressors of life with a rare disease, life has been an unimaginable roller coaster ride! I am so honored to contribute a few reflections for this memorable EP milestone and issue.

I remember thinking our family was so alone in coping with all the uncertainties we faced with Sturge-Weber syndrome in our lives. Yet, each day as we navigated the plethora of doctor visits and the usual new parent joys and anxiety, we would search in the library and ask doctors for answers. Snail mail and long-distance telephone charges put you in touch with the few families an emerging organization, National Organization for Rare Disorders (NORD) shared with us. We cherished so much the proverbial Light of Hope after visiting with other families with Sturge-Weber syndrome! Awareness and advocacy were just as key as providing support and resources.

The first NORD conference I attended representing the Sturge-Weber Foundation was so educational and the collaboration amongst the burgeoning rare disease organizations was exceptional. We bonded over shared experiences and parenting matters while we found many common challenges pertaining to governance, fundraising, and communications. The NORD staff were so integral to hosting excellent conferences and networking people and organizations. Jean Campbell particularly was, and is like Auntie Mame! I was able to find common threads and research leads in Sturge-Weber syndrome after visiting with other leaders and researchers that previously we might not have thought of without the brainstorming.

There was no internet back then and expensive long-distance telephone charges united us to raise our voices to get research funding parity at the National Institutes of Health. Abbey Meyers, NORD President, was and is a force to be reckoned with, and she set an example of how to be a fearless leader who never takes no for an answer! It was a privilege to give back to the community, serving 10 years as a NORD Board of Director.

Since then, there have emerged other umbrella organizations similar to NORD that, in my opinion, have their primary focus on marketing and advocacy. No longer is our world the one- stop-shop for vetted information, which is a blessing and a challenge. Critical thinking is a must, to sift through the plethora of data and hype on the internet. Have articles and facts stated been verified by medical authorities? Is there transparency on where the donations are spent? Is a categorical statement supporting an "xyz" treatment or certain physician by one parent the right fit for you and your family? Only you know, and if you don't, then ask your physician and do your homework.

Not-for-profit organizations typically know how to watch expenses and maximize contacts to ensure that patients and their families get the most bang for that donated buck! Kathy Hunter, International Rett Syndrome Association (IRSA) Founder, was the best at optimizing donations and getting donated products and services! She taught all of us who were new to operating organizations how to partner with pharmaceutical companies. There just wasn't any doubt that we would all succeed by sharing resources, contacts, and concepts. The camaraderie was and still is the best part of coping with a rare disease and operating a not-for-profit organization.

THE FUTURE IS BRIGHT: Karen Ball with daughter Kaelin and family sharing a happy moment. "It's interesting to look back and see the breadth of changes that have occurred in communications, patient engagement and support, physician education and awareness and, of course, research."

It's interesting to look back in the reveal of time and see the breadth of changes that have occurred in communications, patient engagement and support, physician education and awareness and, of course, research. Each generation has something new to offer to improve in all these areas, which leads to faster and greater impact. Tweaking ideas and pulling in new technologies to meet the patient, family, doctor and researcher right where they are in their respective rare disease journey has been key to many breakthroughs and research successes.

There are organizations that have adapted to all these changes and they still thrive and, sadly, many that were splintered by egotistical individuals who watered down the donation and resource pools, only to either merge organizations back again or die off. We HAVE seen many changes at the Sturge-Weber Foundation in 34 years! Thanks to my mentors, cherished volunteers and dedicated donors, we have weathered organizational and economic challenges and reveled in the GNAQ gene mutation discovery. Thanks to the Office of Rare Disease (now at NCATS) and their AMAZING staff, we all put our heads together and learned from one another to develop best research practices, funding opportunities and how to apply for them, and to participate in advocacy on the Hill to spur even more funding for the NIH and FDA. It has been a privilege to fight on the frontlines with so many dedicated men and women and to celebrate so many wonderful milestones together!

The Sturge-Weber Foundation started in an unfinished basement with donated Amoco furniture. The Betty Ford Award and Ann Landers column brought funding and awareness. Building blocks provided by each person bringing what they knew and who they knew to the cause created the successes we have achieved thus far. Today, 27 SWS Clinical Care Network sites are established across the country. Like many organizations, there is an online registry to collect critical natural history data. Volunteers have been and will be at the heart of organizations who create lasting impact for their respective rare disease. Never think that you are not an important piece to mission success! EVERY dollar raised and EVERY little bit you promote, engage and share is critical. It just takes one person, one moment of coincidence or collaboration and whole new frontiers can be opened that we never thought possible. Just say Yes!

There was a rare disease mom, Arlene, who had a son die from her rare disease. I'll never forget, she said one time she would not have started her organization. It was not because it hadn't done well, but she said you can never get back lost time. So many conferences, meetings, phone calls, communications to answer to keep the momentum going were just part of the job. Today it is even harder to shut out the world and truly focus and be present. After 34 years, I truly understand what she was saying!

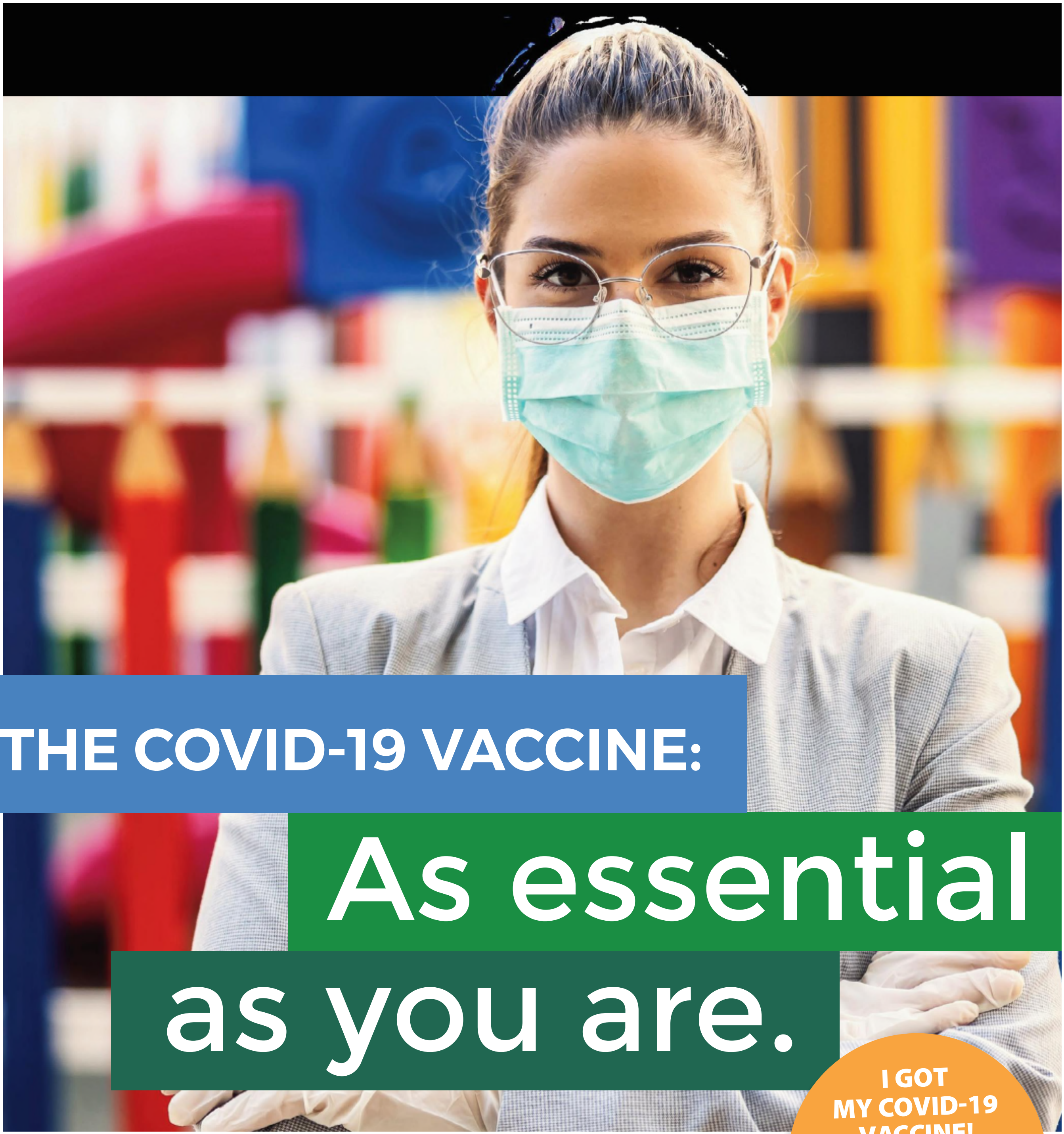
Please give yourself a present and BE present. Time flies by way too fast and you can't get it back. The future is bright as we continue the tradition of fighting for rare disease awareness, research and engagement!

I look forward to seeing how the next generation transforms the community and gives back for their loved ones and to honor all those who lead the way. •

ABOUT THE AUTHOR:

Karen L Ball is the founder and Chief Executive Officer of The Sturge-Weber Foundation (SWF). The SWF was incorporated in 1987 following the birth and Sturge-Weber syndrome diagnosis of her daughter, Kaelin. The incorporation of the SWF starting in an unfinished basement today provided the foundation and collaborations which led to the GNAQ gene mutation discovery, first animal model, and a burgeoning 27 site Clinical Care Network. "The stronger the wind, the tougher the trees."

PHOTO COURTESY RICK GUIDOTTI



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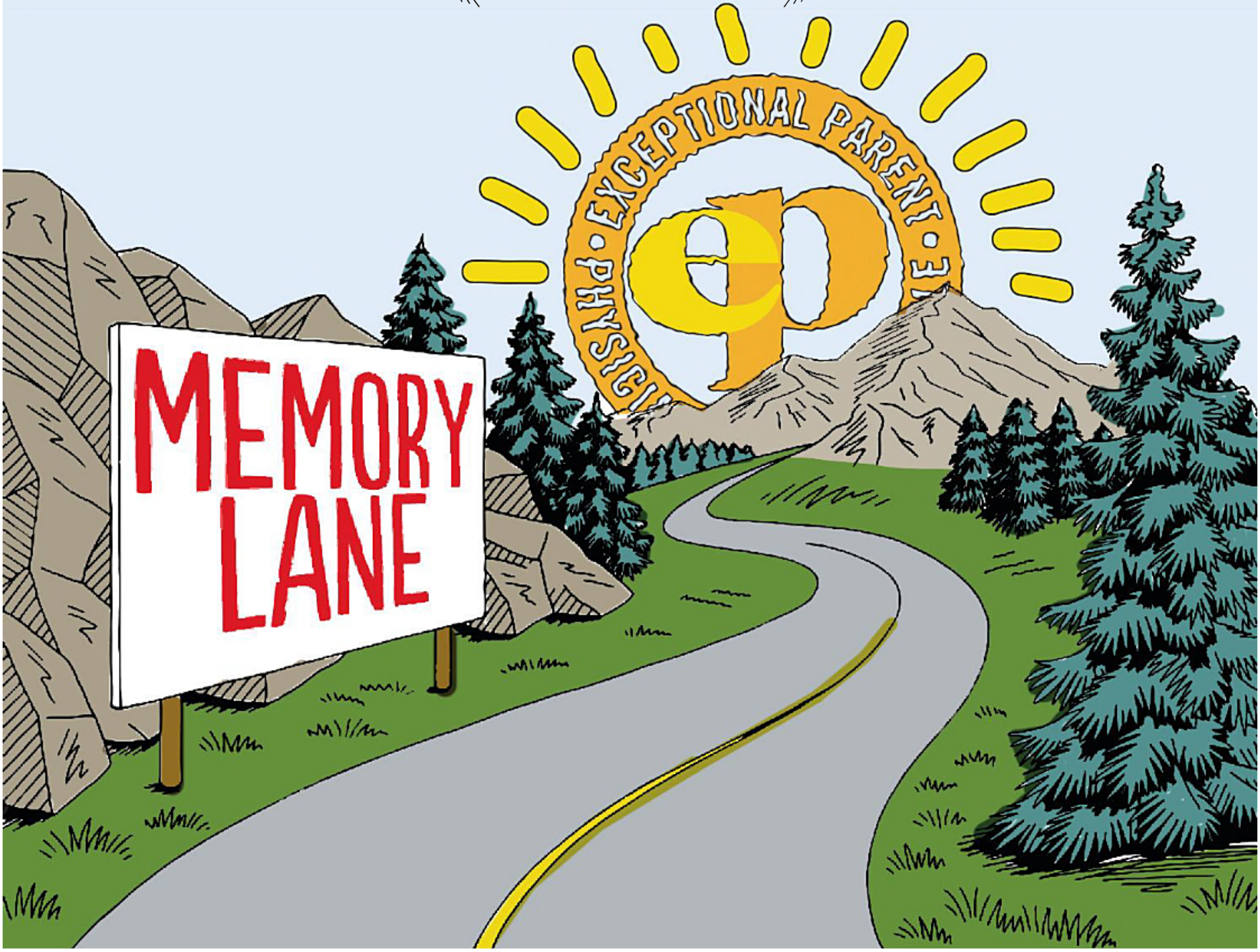


A BEHIND-THE-SCENES JOURNEY
THROUGH HALF OF EP'S 50 YEARS

BY VANESSA B. IRA

I remember the summer day in 2000 when EP Magazine's staff drove, convoy style, to Massachusetts for dear Max Schleifer's funeral. It was raining heavily, the skies commiserating with those of us in our cars whose hearts were aching over the sudden passing of our Editor in Chief. Having been with EP Magazine *(then called* Exceptional Parent*) for five years at that time, this for me had to be the saddest day of all. Yet, I also felt blessed for having worked closely with Max for over three years and been in the presence of one who had great respect and regard for all people with special needs.*

Through 21 years since that day, there have been countless (mostly positive and “fun”) moments connected with *EP* that are worth retelling. Certainly, long-time EP readers may recognize some of the leads and supporting players in these stories. As *EP* ’s current, brilliant Editor in Chief, Dr. Rick Rader, joins the editorial team in putting the finishing touches to this Golden Anniversary issue, memories of all things *EP* – illuminated by so many heroic people (with special needs, exceptional parents, spouses, caregivers and advocates) – march through my mind like a parade I do not wish to end. Won’t you join me in taking a behind-the-scenes journey of *EP* ’s history through the past quarter-century?

MAX AND ESTHER

I remember Massachusetts-based Max coming to our Oradell, NJ, office often for editorial meetings where I would listen intently to his ideas for articles, his wisdom, and deep knowledge of the disability field. Our Harvard-educated editorial leader and *EP Magazine* co-founder was an intellectual with a great sense of humor, a twinkle in his eye, and a distinct Boston accent. “Vehh-nesssa,” he called me. Max always came to our office with his leather satchel packed with reading material and, of course, his wife Esther was never far behind. A mother figure to us, she had as much love for the special needs community as her husband.

How can I forget witnessing a rather strange scene during one of our brainstorming sessions at a New Jersey diner? One day, after we had just wrapped up discussing urgent editorial matters, erudite Max moved to a chair next to our quintessential smooth-talking New York City salesman Anthony (*Ant-neeh*, as we called him) and launched into an animated chat with him. Curious, I tilted my head their way to find out what it could be about; Anthony couldn’t possibly have been gathering more information about special needs Schools, Camps and Residences. There were just too many expressive hand gestures and Max’s soft voice was louder than usual. Yup, it was something so unexpected, even charming. Anthony was exchanging detailed notes with Max on… Filene’s Basement discounts!

What about the time Max and Esther flew to Memphis, TN, with the staff for one of *EP*’s first disability conferences developed by (then-CEO) Joe Valenzano? Climbing into our rented mini bus a little late for departure time, Max and Esther told us that they just returned from a short side-trip to Graceland. As Max sheepishly put it, they had just taken in “a piece of Americana.” What he didn’t know was, earlier that day, some from the *EP* staff had to turn away a giddy group of sight-seers who spotted our conference’s welcome banner by the entrance and mistakenly believed they had discovered an “Elvis Presley” (“EP”) Convention in Memphis. Levity aside, *EP Magazine* had a well-received conference that weekend, which opened the door for more EP-developed events such as the World Congress on Disabilities (WCD).

Several years after Max’s passing, we stayed in close touch with his widow, Esther; she was such a valued fountain of ideas for feature stories (aside from being a rabid baseball fan like us, though she rooted for the “wrong” team). One of the best ideas Esther shared was one we used for an article regarding a school (ECLC of New Jersey) that took in a Labrador Retriever named Patrina to be part of its staff and for many years, gave great joy and comfort to dozens of the school’s students with developmental disabilities.

IN AWE OF THE FAMILIES

I remember, during my early days with EP, staff members were assigned to attend more than a dozen trade shows or special events per year that were held across the United States. This provided us with the unique opportunity to meet, in person, so many extraordinary families touched by specials needs. We cherished listening to them while appreciating their courage and resourcefulness, and we made sure we took note of all the issues that mattered most to them. Those of us manning *EP* ’s booths at the conferences would get lost in conversations with the families. As they poured their hearts out to us, how we wished the typically buzzing exhibit halls would quiet down, so we wouldn’t miss a word of what the parents (or caregivers) wished to share with *EP*’s other readers.

Whatever information we couldn’t gather at the conferences, we received through snail mail, for our magazine’s department called “Search and Respond”. Parents would mail their letter to *EP*, in search of other families who might be familiar with their child’s disability, so they could learn from their experiences. The editors would wait for the right response, also via snail mail, “match” it with the original inquiry – and then publish the “search” question next to the response. There were times the right match would take months to accomplish, but we were always pleased when *EP* could serve as a conduit for connecting the families. When the “World Wide Web” exploded in the late 1990s, and much-welcome and instantaneous communication between families became a reality, *EP* built its first website (today, the URL is **www.epmagazine.com**).

SHOPPING CARTS AND 75,000 EPS

In 1995, with a tiny staff of about 15, EP attended the Special Olympics World Summer Games in New Haven, Connecticut, armed with nothing but shopping carts and good walking shoes, to distribute 75,000 copies of *EP Magazine* to the event’s spectators. The shopping carts were rented by the baseball team of CEO Joe (who coached at Ramapo), and the young men gave us a much-needed helping hand that day. The President of the United States attended the event, and the venue was packed with athletes and their friends and family, all sharing the joys of achievement and camaraderie. At the end of the long, hot day, I didn’t feel any fatigue at all.

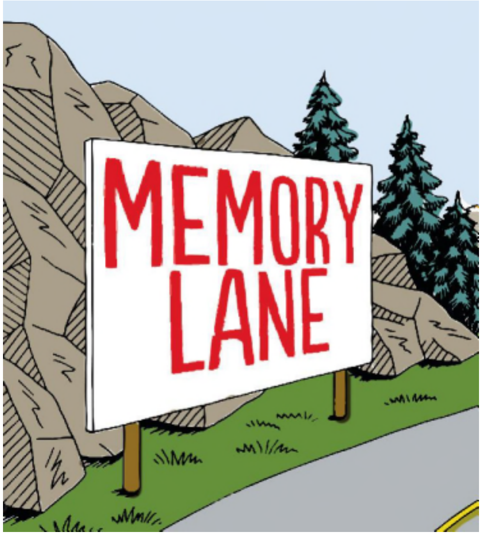
It was during the early part of the new century when *EP* read a piece of news about the old Yankee Stadium getting some bad press for not being accessible for people with physical disabilities. Joe challenged one of our young sales people to help pitch an idea to Steinbrenner’s team. The proposal was for *EP* and the Yankees to host a Disability Awareness Night (or

"DAN") honoring hero advocates of the community, pre-game, right on home plate. They liked the idea. We ended up hosting two DANs during the initial year (the Red Sox wanted one as well), a dozen the following year, and then 27 on the best year, covering most of Major League Baseball's ballparks across the country.

THE GOOD DOCTORS

I remember being assigned to represent *EP* for a DAN event at the Milwaukee Brewers' ballpark. Our honoree was Dr. Raymond (Ray) Chun, a giant in the field of pediatric neurology who was a founding member of the Child Neurology Society (CNS), the major professional organization of pediatric neurologists in the country. I met Dr. Chun and his family prior to home plate ceremonies. I recall congratulating our honoree and, to break the ice, started talking about what I believed to be something Wisconsin-related – specifically, the story one of my *EP* colleagues had recently told me, of a small plane filled with Green Bay Packers fans who were saved from horrific crash-landing head injuries by their Cheesehead gear (after the pilot warned them to "brace for impact"). I asked Dr. Chun if he ever heard of this amazing story, to which he responded with an amused smile, "But my dear, that's an urban legend."

The following week, Dr. Chun mailed me a surprise package with a genuine Packers Cheesehead. He included a sincere, handwritten note, thanking me for hosting his family for DAN and (of course) reminding me of the urban legend I fell for. Dr. Chun is one of many wonderful healthcare professionals I've come in contact with at *EP* for to cover magazine stories or collaborate with on educational webinars. In all my years with *EP*, working on various projects for the special needs community with physicians or nurses, I've noted how down-to-earth these people are. No egos. Just a mutual desire to do the very best work for the community. The same thing holds true in 2021 as I work with various physicians and dentists from the American Academy of Developmental Medicine and Dentistry (AADMD), especially long-time editorial contributors Dr. Steve Perlman and Dr. Barry Waldman, the most enthusiastic and positive editorial collaborators one will ever meet.



THANKS FOR THE MEMORIES: "Reminiscing about milestone events inevitably invites introspection as well as a good dose of gratitude. The special needs community inspires me, hopefully, towards the next milestone year."

HOPE – ALWAYS

Another DAN event to remember was the time *EP* honored Eunice Shriver at Fenway Park in 2002. The plan was for EP to take Mrs. Shriver to Fenway from Washington D.C., where she was based. In the end, one of *EP*'s friends generously lent us his Gulf Stream jet, so we were able to fly Mrs. Shriver, Tim Shriver, and a few Special Olympics athletes to the Boston DAN venue. I remember sitting quietly behind our iconic honoree, just savoring the whole experience. I was also listening to a light conversation between CEO Joe (Yankees fan) and Tim Shriver (Red Sox fan) about the legendary baseball rivalry. The former kept ribbing the latter about rooting for a team that (back then) had not won a World Series championship in a lifetime. "Ah… but there's always hope," Tim responded. For several reasons, I've never forgotten that line.

In the late '90s, prior to the time *EP* staff started working from their own homes (years before the COVID-19 pandemic made it a common practice), I remember my colleagues and I would gather for a yearly *EP* "family picture" under one of North Jersey's most ancient trees. Some of those published photos included Julie Chistensen from our editorial team and her then-toddler Brielle (who has a mitochondrial metabolic disorder, now in her late twenties); as well as long-time *EP* friend and Editorial Board Member Lauren Agoratus with her young daughter, now a young adult with medically-complex special needs. I am grateful to them, and to all exceptional parents, for all they teach us daily about being tireless givers of care and support for their loved-ones.

HERE'S TO OUR NEXT MILESTONE

Reminiscing about milestone events inevitably invites introspection as well as a good dose of gratitude. Personally, I am thankful to my own mother, who became physically disabled around the time I first joined *EP*; she, like other people who have special needs, taught me to keep things in perspective. Mom showed grace at all times and continued to accomplish her personal goals despite suffering from constant pain. As they say, you have to live your life.

I am also grateful to the hundreds of disability organizations and professional associations *EP* has closely collaborated with through the years, including United Cerebral Palsy (UCP), the AADMD, Epilepsy Foundation, SPAN, The Arc, the National Organization for Rare Disorders (NORD), Special Olympics, the Exceptional Family Member Program (EFMP), and so many more. All have helped light *EP*'s path with their own work for the community.

EP Magazine has remained standing, and standing tall, through very good times and economic turmoil. These days, thanks in great part to a small but dedicated team, including our publisher, Len Harac, Faye Simon with business development, our book designer Leverett Cooper, and of course Dr. Rader (who succeeded Max in 2000), we've managed to sprint past the horrific 2020 pandemic. The special needs community inspires me and I am sure, my *EP* colleagues, to keep moving forward… hopefully, towards the next milestone year.

A Very Happy Golden Anniversary, EP! •

ABOUT THE AUTHOR:

Vanessa B. Ira has been a member of the EP Magazine (Exceptional Parent) family for more than half of the magazine's 50 years of publication. She oversaw and managed EP's first website as well as several of its successful health care webinars. She is currently EP's Managing Editor.

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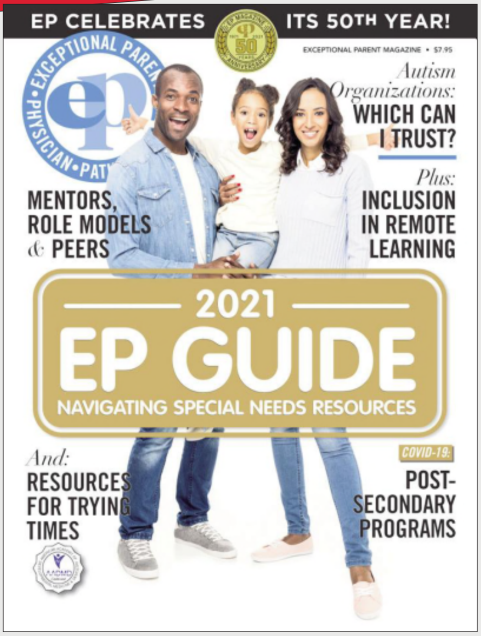

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EP MAGAZINE: THE JOURNAL FOR SPECIAL NEEDS FAMILIES AND PROFESSIONALS

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GOLDEN ANNIVERSARY
50 YEARS OF EP
1971 – 2021

Handicap or Disability

[Editor's Note: The following is the first editorial in the first-ever issue of *Exceptional Parent Magazine* in June of 1971.]

Handicapped... Crippled... Disabled... are common words often used to mean the same thing; somehow they frequently sound either critical or pitying. We are,all prisoners of our habits to some extent; sometimes we slip and use words without thinking.

We prefer that the term "crippled" not be used; it has too many negative connotations (even though a distinguished organization bears the word in its title). We also prefer that the word "handicap not be used, but we recognize that it is a commonly used term. We too are in the habit of using it.

Dr. Beatrice A. Wright, of the Department of Psychology at the University of Kansas, thoughtfully discusses this issue in her very fine book, *Physical Disability – A Psychological Approach.** She indicates a preference for the term "disability" and points out that the physically disabled person is also a physically abled one. She quotes K. W. Hamilton** who proposes a distinction between the terms "disability" and "handicap." Hamilton sees disability as an objective physical or mental impairment which could be described by a physician. A handicap is the result of the effects of that disability – the obstacles it places between the person and his maximum functioning level. A disability refers to a medical condition; a handicap refers to a disability combined with a complicated set of social and psychological forces.

For example, many people have conditions which are disabilities, but are not really handicaps – slightly protruding teeth, a slight hearing loss or a moderate visual problem. All of these can be controlled by reasonable, readily available means – braces, hearing aids and glasses. Prompt provision of the appropriate device neutralizes the effects of the disability and (providing there are no adjustment problems) helps the person become functionally normal.

Handicap is a relative term. For example, children are not as strong as adults, nor are women as muscular as men (although in many ways as strong and certainly more durable). However, we do not consider either handicapped.

Dr. Wright concludes by saying "a physical attribute is a physical handicap only when it is seen as a significant barrier to the accomplishment of particular goals. This means that, in the individual case, a physical disability may or may not be a physical handicap. Moreover, a physical attribute may become handicapping not because it is physically limiting but because it adversely affects social relationships." (from Dr. Wright's book, page 10).

We have been discussing the use of words. Words express attitudes. The attitudes that we have shape our behavior. Disability expresses the attitude that the child and the parent are capable of mastering together the challenges that they will face. The word handicap expresses our concern that the child has such severe limits that he will never be able to master the problems of growing up. Our consistent use of the term disabled reflects those attitudes which are necessary for growth.

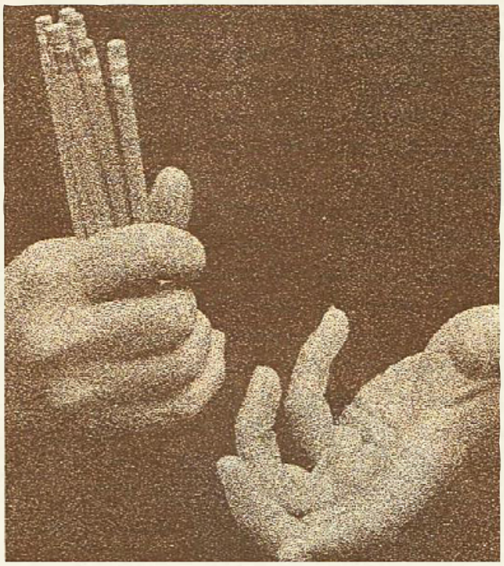
A child may have a disability, but whether or not he grows up to be handicapped depends on how his family. his neighbors, his teachers and other professionals regard him and treat him. If he is overprotected and undereducated, if he is not allowed to take reasonable risks and become as self-sufficient and independent as possible, he may well become a handicapped adult.

---

*Wright. Beatrice A., *Physical disability-a psychological approach*. New York: Harper and Row, 1960.

**Hamilton, K. W. *Counseling the handicapped in the rehabilitation process*. New York: Ronald, 1950.

handicap



pity
charity
loneliness
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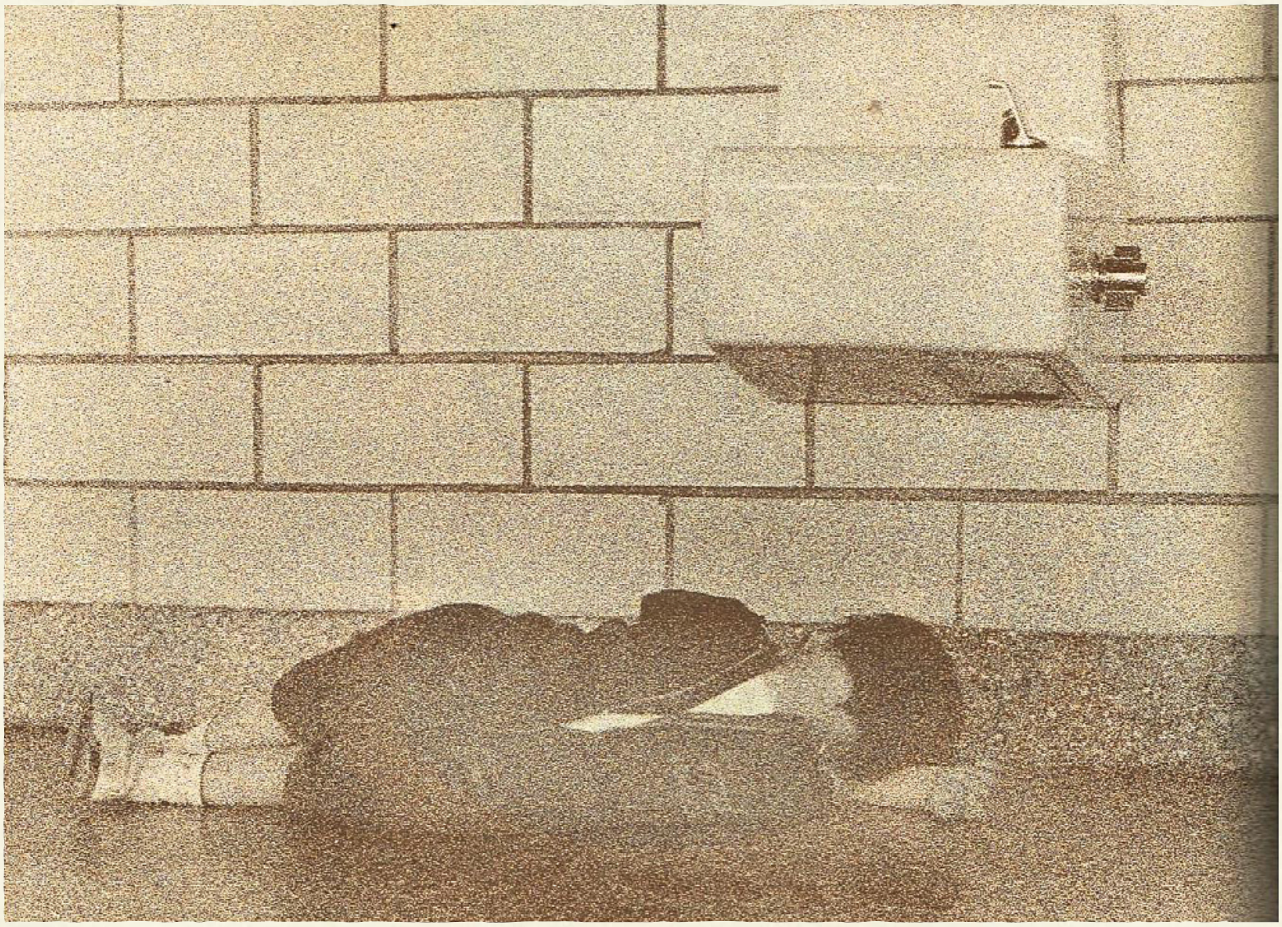


disabilty

participation
competence
independence
striving
confidence
respect
achievement

INTRODUCTION: EP MAGAZINE SLEEP SERIES

Why Do We Sleep?

BY BETH MALOW, MD, MS AND ALTHEA ROBINSON SHELTON, MD, MPH

> *"It is a common experience that a problem difficult at night is resolved in the morning after the committee of sleep has worked on it."*
>
> ~ John Steinbeck

Welcome to our sleep series. Over the next two years, we will be publishing an article every other month on sleep and sleep concerns in people with disabilities across the lifespan. In future articles on sleep in EP Magazine, *we will explore specific sleep conditions, how to improve sleep, and the impact of a good night's sleep on health and daytime functioning. While we don't yet know the exact function of sleep, we know how we feel when we don't sleep – grumpy, grouchy, and more apt to send an email or social media post we will regret later! We also know that sleep problems can be addressed and when we and our children are sleeping better, everyone is happier. We look forward to taking a deep dive into sleep with you!*

– Beth Malow, MD, MS and
Althea Robinson Shelton, MD, MPH,
Vanderbilt University Medical Center

In this article, the first of a series on Sleep for *EP Magazine,* we will delve into the possible functions of sleep, and why we sleep. Along the way, we will bring in the history of sleep, including Shakespeare, Proverbs, and Philosophers. We will focus not only on what clinical sleep experts consider to be sleep's functions, but humanists as well. Why we sleep remains a mystery, although there are myriad benefits of sleep on our health and well-being.

Let's start with why we sleep. The short answer – we don't know! There have been several theories put forth, however.

The first is the *Inactivity Theory:* Animals that can stay still and quiet are less apt to be targets for predators. So, we have evolved to be still at night and quiet. Although one would think being awake, still, and quiet would be better when dealing with tigers and other predators…

In fact, some animals sleep with one half of their brain at a time, such as dolphins, so they can still be awake to ward off predators. So, the Inactivity Theory has fallen out of favor.

The second theory to consider for why we sleep is the *Energy Theory.* In a setting where food is limited and needs to be searched for, sleep allows us to reduce our demand for energy, especially when it is harder to search for food (such as at night). However, as any of us who have gotten the munchies at 2 am know, this theory may not relate to modern times.

However, since antiquity, sleep has captivated the imaginations of ancient healers, scribes, poets, philosophers and scientist as evidenced by mythologies, books, plays and art.[1] The ancient Egyptians, as far back as 4000 B.C., used sleep as therapy, and had treatment for sleep disorders, such as insomnia. The medicine of ancient Egypt is one of the oldest documented scientific disciplines. The Egyptians were the first to mention the use of opium for the treatment of insomnia.

Egyptian medical writings stated that thyme was beneficial in reducing snoring. They also investigated the nature of sleep and dreaming and interpreted dreams using "dream books." [2]

The Ancient Greeks and Romans furthered dream interpretation but, in addition their philosophers and physicians, stepped away from the mystical and began to postulate on how sleep and the human body functioned together. The Greco-Roman time period is where you first find documentation of accounts of sleep and dreaming based on reason, rather than mystical knowledge.[3] Circa

LAND OF NOD: "Why we sleep remains a mystery, although there are myriad benefits of sleep on our health and well-being."

450 BC, Alcmaeon provided the first reason-based theory of sleep. He believed that lack of circulation (blood carrying veins) to the brain caused sleep, a spell of unconsciousness. Following him, there were multiple other philosophers with non-mystical theories of the process of sleep. However, Aristotle is the first of the Greek philosophers to provide the most comprehensive written reason-based account of sleep and dreaming. He wrote three full essays on the subject.[4] Aristotle believed the process of sleep commenced with the consumption of food which thickened and heated the blood. The food, which he termed "solid matter", would then rise to the head where it was cooled by the brain and the subsequent reverse flow back downward caused a "seizure" in the heart which caused sleep. Wakefulness occurred when digestion was completed with a separation between the "solid matter" and more pure blood. He also rightly believed that sleep kept living beings alive.[5] Hippocrates, the most famous physician in Western civilization, wrote that sleep disturbance was something to take note of and use in the diagnosis and prognosis of disease. In Regimen in Acute Diseases, he offers advice for insomnia, "if sleep should not come, a slow prolonged stroll, with no stops, should be taken." Throughout his multiple texts he discussed the importance of sleep and even prescribed sleep as a treatment for a variety of conditions, along with diet and exercise.[5]

In our ever-divided world, we agree on few things, but most people would agree that sleep is important. Over one-third of adults in the United States report insufficient sleep. However, often sleep is the first thing that gets sacrificed in order to accomplish all our obligations. In Macbeth, Shakespeare writes, *"Sleep that knits up the ravell'd sleave of care, The death of each day's life, sore labour's bath, Balm of hurt minds, great nature's second course, Chief nourisher in life's feast."* He is exhorting the restorative nature of sleep.

Which leads us to discuss our favorite theory of "why we sleep," the *Restorative Theory:* Sleep "restores" and repairs what is lost in the body when we are awake. Think of sleep as a reset button, similar to restarting our computers so they work better. This restoration can occur for both physical and mental conditions. For example, one theory of how sleep prevents Alzheimer's disease stems from sleep getting rid of waste products that accumulate in our brains overnight, as described below. We also feel less stressed and more rejuvenated – ready to take on the day – once we have slept.

PERCHANCE TO DREAM : THE IMPACT OF A GOOD NIGHT'S SLEEP ON HEALTH AND DAYTIME FUNCTIONING

We cannot overstate the importance of sleep. Getting enough sleep makes it easier to prevent and manage disease. Too little sleep and poor sleep quality have been associated with severe health outcomes. So, let us briefly delve into some of these health outcomes. In future articles, we will discuss these more in depth.

Attention and Memory

As sleep neurologists, problems with memory and focusing are something that we often see, and we work with psychologists to help diagnose these problems. Paying attention is one of the most studied problems.[6] The fewer hours that we sleep, the more lapses in attention we have. In addition, research shows that short sleep duration causes problems with our memory, decision making, and processing speed.[7] Poor sleep is linked to the build-up in the brain of a chemical called beta amyloid, which results in Alzheimer's disease.[8] Beta-amyloid buildup also occurs in Down syndrome, and has been connected with Alzheimer's disease symptoms as individuals with Down syndrome age.[9]

Seizures

Seizures are common in some intellectual and developmental disabilities (IDD), such as autism spectrum disorder and Down syndrome, and are more common in those with more severe forms of IDD.[10] Seizures have a reciprocal relationship with sleep, with disrupted sleep making seizures more likely. In turn, seizures can disrupt sleep. Treating sleep problems can improve seizure control.[11]

Cardiovascular Disease

Poor sleep, and chronic sleep loss, have been linked to heart disease[12] and high blood pressure.[6] Not sleeping enough hours increased a person's chances of high blood pressure by 20%.[13]

Type 2 Diabetes

Type 2 diabetes has become an increasingly common chronic condition in the United States. Not getting enough sleep results in a 33% increased risk of developing diabetes.[14] When people sleep too few hours, they are more likely to eat unhealthy foods.[6]

Weight Gain

Weight gain, including obesity, often results when people are not getting enough sleep, especially young adults.[15] With chronic sleep loss, there are changes in leptin and ghrelin which are two hormones that regulate how hungry or satisfied we feel after we have eaten. On the bright side, getting more sleep can help with weight loss.[6]

Mood

Sleep and mood have a reciprocal relationship. Mood disorders, such as anxiety, can often make sleep worse but chronic sleep loss can also worsen mood. Shortened sleep can make depression more likely.[16] In children with developmental disabilities, like autism spectrum disorder, sleeping less can go along with depression and obsessive-compulsive disorder.[17] The promising news is that it's possible that depression symptoms may improve with sleeping more.[18]

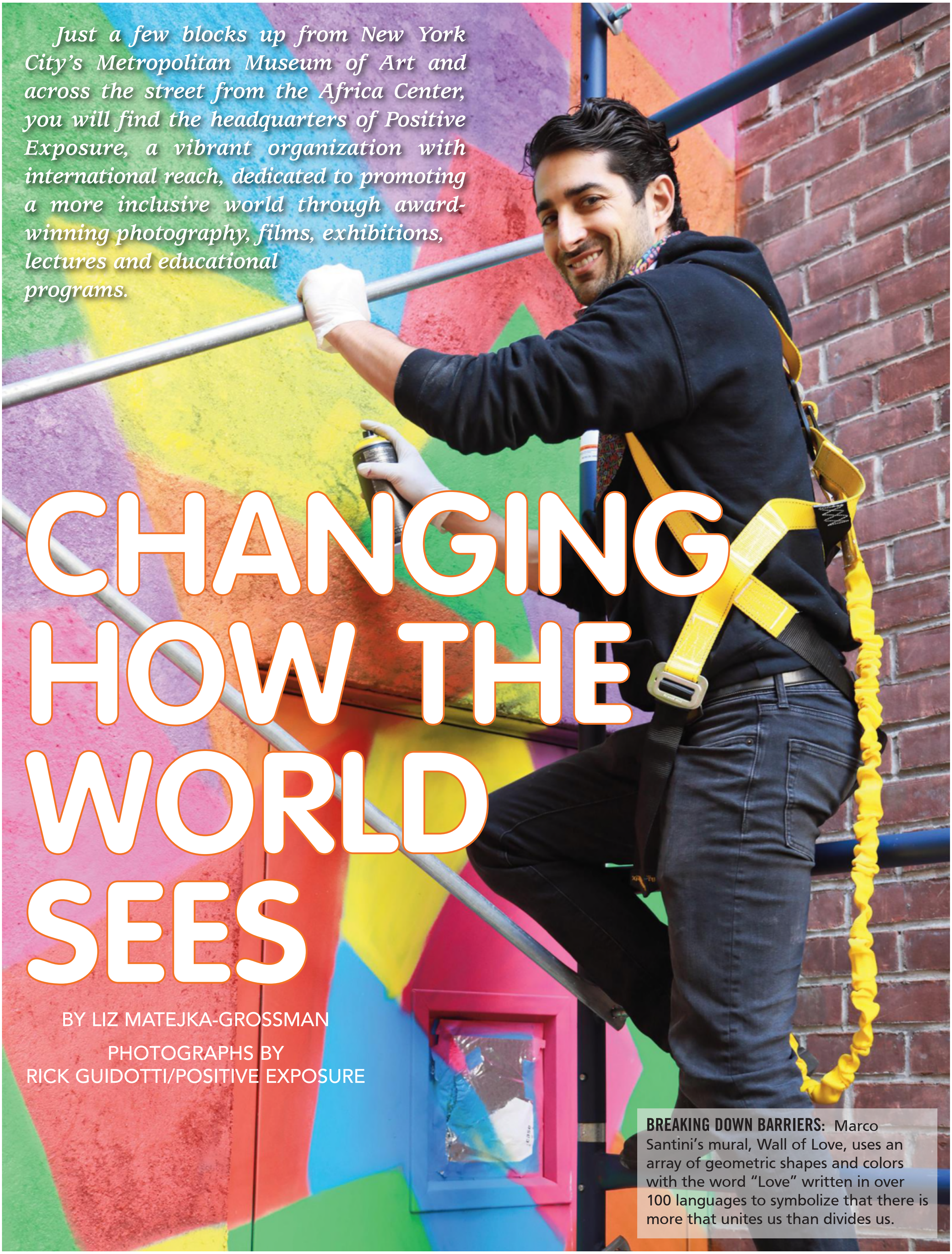
To summarize, while WHY we sleep is still a mystery, the importance of sleep has become clear. In future articles, we will dive more into how sleep is affected by genes and other factors, and what you can do to make sure you get your best night's sleep.

ABOUT THE AUTHORS:

Dr. Althea Shelton's research and clinical practice is focused on sleep disorders in children and adolescents with neurodevelopmental disorders.
Dr. Beth Malow's research and clinical practice is focused on sleep in autism across the lifespan, including treatments with behavioral approaches and medications.

References

1. Borbely A. (1984). Secrets of sleep. New York: Basic Books.
2. Asaad T. (2015) Sleep in Ancient Egypt. In: Chokroverty S., Billiard M. (eds.) Sleep Medicine. Springer, New York, NY.
3. Barbera J. (2008). Sleep and dreaming in Greek and Roman philosophy. Sleep Med.;9(8):906–10.
4. Gallop D. (1996) Aristotle on sleep and dreams. Warminster: Aris and Phillips.
5. Barbera J. (2015) The Greco-Roman Period. In: Chokroverty S., Billiard M. (eds.) Sleep Medicine. Springer, New York, NY.
6. Grandner MA. (2017) Sleep, Health, and Society. Sleep Med Clin.; 12(1):1-22.
7. Goel N, Rao H, Durmer JS, et al. (2009) Neurocognitive consequences of sleep deprivation. Semin Neurol ;29(4):320–39.
8. Winer JR, Mander BA, Kumar S, Reed M, Baker SL, Jagust WJ, Walker MP. (2020). Sleep Disturbance Forecasts β-Amyloid Accumulation across Subsequent Years. Curr Biol. 2;30(21):4291-4298.
9. Carmona-Iragui M, Videla L, Lleó A, Fortea J. (2019). Down syndrome, Alzheimer disease, and cerebral amyloid angiopathy: The complex triangle of brain amyloidosis. Dev Neurobiol. 79(7):716-737.
10. Devinsky, O., Asato, M., Camfield, P., Geller, E., Kanner, A. M., Keller, S., Kerr, M., Kossoff, E. H., Lau, H., Kothare, S., Singh, B. K., & Wirrell, E. (2015). Delivery of epilepsy care to adults with intellectual and developmental disabilities. Neurology, 85(17), 1512–1521.
11. Malow BA. Sleep, epilepsy, and autism. (2004). Mental Retardation and Developmental Disabilities Research Reviews 10: 122–125.
12. Amagai Y, Ishikawa S, Gotoh T, et al. (2010). Sleep duration and incidence of cardiovascular events in a Japanese population: the Jichi Medical School cohort study. J Epidemiol.;20(2):106-10.
13. Meng L, Zheng Y, Hui R. (2013) The relationship of sleep duration and insomnia to risk of hypertension incidence: a meta-analysis of prospective cohort studies. Hypertens Res. 36(11):985-95.
14. Shan Z, Ma H, Xie M, et al. (2015) Sleep duration and risk of type 2 diabetes: a meta-analysis of prospective studies. Diabetes Care 38(3):529–37.
15. Grandner MA, Chakravorty S, Perlis ML, et al. (2014). Habitual sleep duration associated with self-reported and objectively determined cardiometabolic risk factors. Sleep Med 15(1):42–50.
16. Liu X (2004). Sleep and adolescent suicidal behavior. Sleep. 27(7:1351–135.
17. Veatch et al. (2017). Shorter sleep duration is associated with social impairment and comorbidities in ASD. Autism Research. 10(7):1221-1238.
18. Dewald-Kaufmann et al. (2014). The effects of sleep extension and sleep hygiene advice on sleep and depressive symptoms in adolescents: a randomized controlled trial. J Child Psychol Psychiatry. 55(3):273–283.



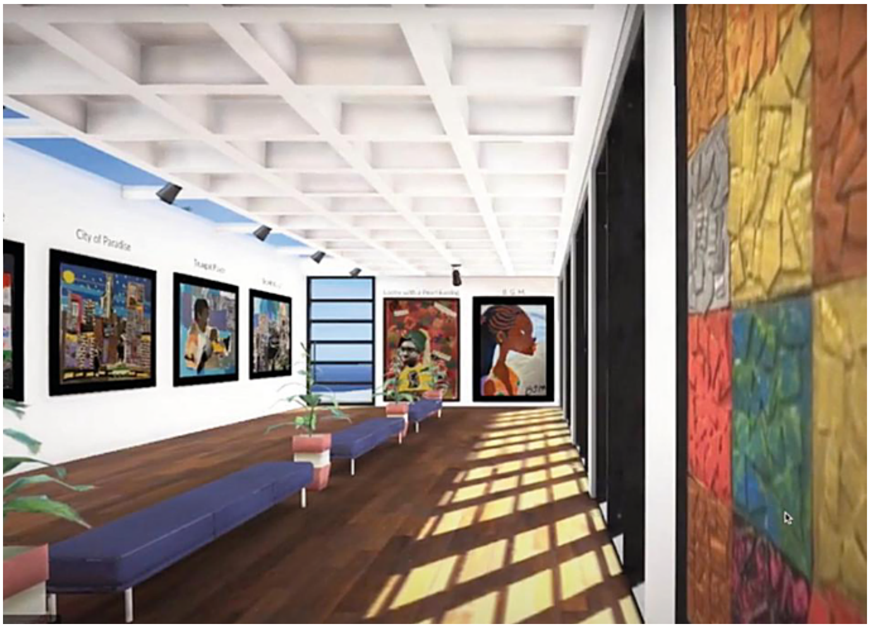
Just a few blocks up from New York City's Metropolitan Museum of Art and across the street from the Africa Center, you will find the headquarters of Positive Exposure, a vibrant organization with international reach, dedicated to promoting a more inclusive world through award-winning photography, films, exhibitions, lectures and educational programs.

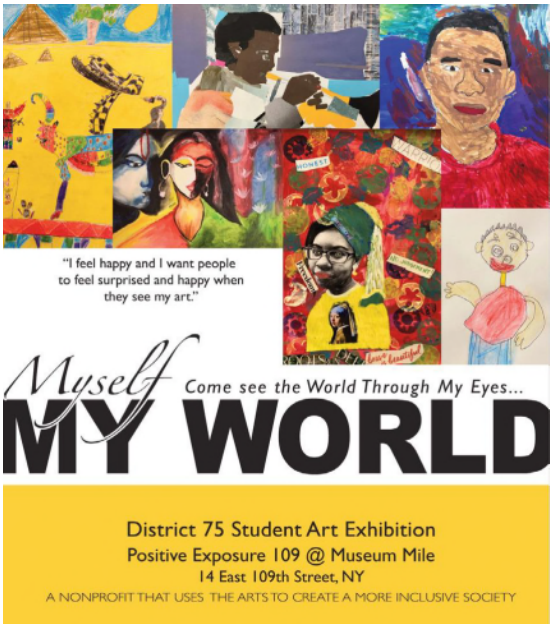
CHANGING HOW THE WORLD SEES

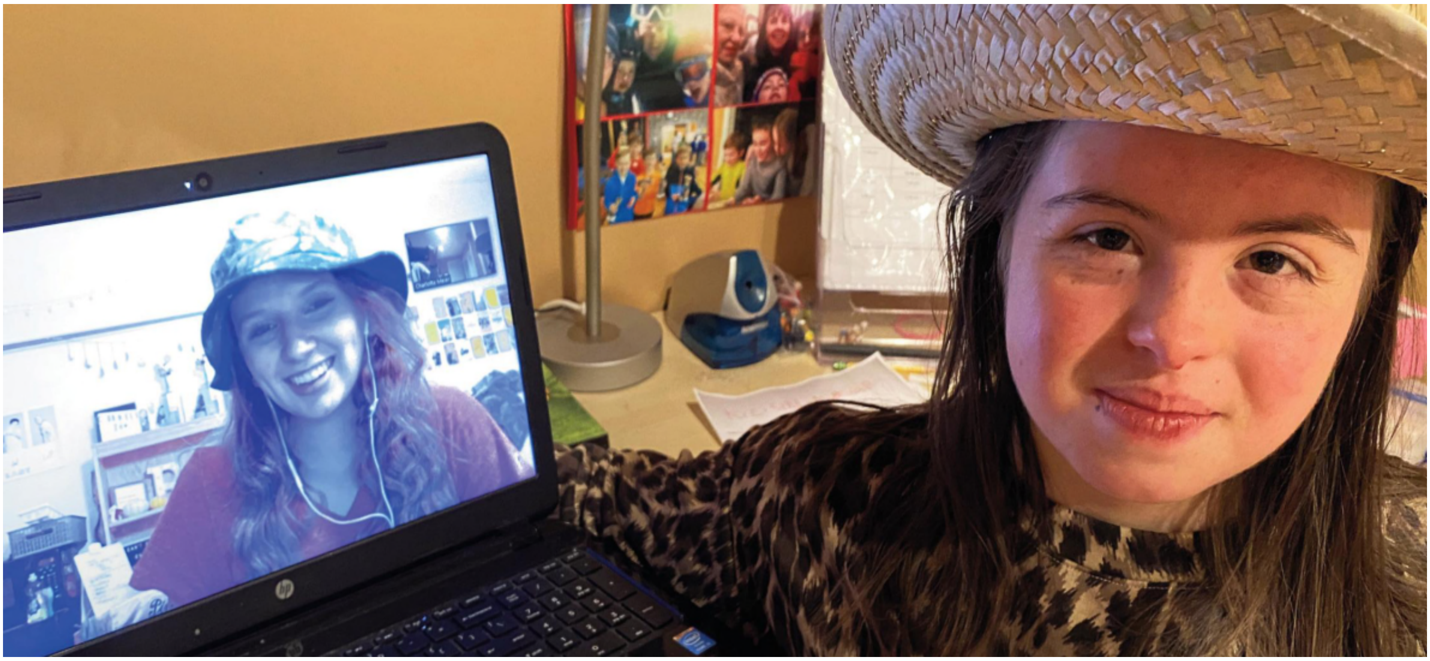
BY LIZ MATEJKA-GROSSMAN

PHOTOGRAPHS BY
RICK GUIDOTTI/POSITIVE EXPOSURE

BREAKING DOWN BARRIERS: Marco Santini's mural, Wall of Love, uses an array of geometric shapes and colors with the word "Love" written in over 100 languages to symbolize that there is more that unites us than divides us.







SHARING EXPERIENCES: *Clockwise fron top left)* The Positive Exposure Gallery serves as a central hub for artists; A poster for juried student exhibition Myself My World; The Cameradery Club photography program was featured in the Positive Exposure Gallery.

For over two decades, Positive Exposure has partnered with diverse communities to create multimedia exhibitions that have facilitated important conversations and needed change, impacting millions of people.

On any given day, Positive Exposure's calendar is filled with lectures to first year medical students, grand rounds, family conferences, photo and film shoots, international disability rights activist interviews, and the development of educational curricula for K-12, college, medical school and beyond.

Its FRAME program (Faces Redefining the Art of Medical Education) is an extensive, web-based film library that has been utilized by tens of thousands of health care professionals in training, clinicians, families and communities.

In each FRAME film, individuals and their families demonstrate the hallmark characteristics of the featured condition, placing front row and center – in medical education – humanity, and the philosophy that is never what you are treating, but who you are treating.

The PEARLS Project, featured in a *New York Times* article entitled Learning Empathy by Looking Beyond Disabilities, is a blog platform created for Positive Exposure ambassadors to share life from their unique perspectives, helping audiences appreciate and experience our shared humanity.

The Positive Exposure Gallery, located just off Central Park North in East Harlem, serves as a central hub for showcasing the

LOVE LETTERS: *(Clockwise fron top left)* Detail from the Wall of Love, a public art installation celebrating Valentine's Day; The inaugural installation of Light Up the Night with Love, Unity and Inclusion; Musical artist Lachi prepares for a video shoot at the gallery.

work of visual, performing, literary and multisensory artists, as well as providing educational, cultural and artist-in-residency programming.

This first-of-its kind space invites the general public to visit, to be wowed, to learn, to engage in dialogue and experience these ever-evolving collections and important, often overlooked, contributions to the art world.

In March 2020, Positive Exposure installed a juried student exhibition entitled Myself My World, in collaboration with New York City's Department of Education's District 75, a citywide program which serves more than 23,000 children with disabilities ages 3 -21 who require more intensive, specialized services. Plans for an opening celebration, school visits and community programming had just been finalized when Positive Exposure was forced to temporarily close its doors due to COVID-19.

Similar to the rest of the world, Positive Exposure transitioned all programming – including the exhibition – to a virtual platform.

Fearful of the isolating effects of the pandemic for communities, already experiencing isolation and exclusion, Positive Exposure Connects was created – a Facebook Live series of energized discussions with activists, advocates, educators, artists, healthcare providers, friends, families and communities.

While most programs continue to be virtual, Positive Exposure has started to open back up safely in accordance with CDC guidelines.

In late January, Positive Exposure called upon its community to come together and create a public art installation for Valentine's

POSITIVE SPACE : ARTISTS AT WORK

Other artists who have been busy – albeit safely – at work in the Positive Exposure gallery include:

WENDY ANN POWELL and ZAZEL-CHAVAH O'GARRA

Wendy Ann Powell is a Professional Dancer, Choreographer and Disability Advocate. Visit: www.backstage.com/u/WendyAnnPowell139 Zazel-Chavah O'Garra is Founder and Artistic Director of ZCO/DanceProject, a physically integrated dance company whose goal is to create performances that are witty, soulful, intelligent, powerful and intriguing. ZCODP seeks to encourage the integration and inclusion of people with disabilities in dance and in society, to present new, exciting, challenging, and inspiring contemporary dance performances to the widest possible audience. Visit: www.zcodanceproject.com/about-444126-458599.html

LACHI

Lachi is an award-winning vocalist, songwriter, composer, producer, diversity and disability inclusion advocate, voice actor and author based in New York City. Lachi began writing songs and short stories at an early age, and has cowritten or collaborated on numerous albums and singles. She has Coloboma of the retina causing legal blindness. Visit: https://lachimusic.com

FULL CIRCLE: *(Right, top to bottom)* ZCO/DanceProject, a physically integrated dance company that encourages inclusion of people with disabilities in dance and in society; The work of Naomi Lawrence, a NYC Fiber Artist based in East Harlem.

Day, as an extension of Positive Exposure's East Harlem Wall of Love by Marco Santini. For his mural – which is located in the courtyard Positive Exposure shares with The Church of St. Edward the Martyr and the New York Common Pantry – Santini used an array of geometric shapes and colors with the word "Love" written in over 100 languages to symbolize that "there is more that unites us than divides us." Building on this concept, Positive Exposure requested that the community submit artwork addressing the theme of Light, Love, Unity and Inclusion.

The community response and submitted artwork was exquisite, kicking off the first in a series of collaborative public art installations based on the theme, Fill the World with Love. This inaugural installation – entitled Light Up the Night with Love, Unity and Inclusion – showcased and illuminated more than 250 pieces of art from around New York City and the globe!

In April 2021, Cornell University Cameradery Club photography program exhibition in collaboration with interested PEARLS Ambassadors was featured in the Positive Exposure gallery, while additional collaborative public installations will occur around New York City in partnership with muralist Marco Santini and Naomi Lawrence, a NYC Fiber Artist based in East Harlem. Visit: https://naomirag.com

To learn more about Positive Exposure, please visit www.positiveexposure.org *Want to visit? Positive Exposure is now scheduling summer and fall "in-person" appointments. To schedule a visit, please email* liz@positiveexposure.org ●

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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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HOW PEER SUPPORTS EVOLVED FROM ONE-TO-ONE HELP TO CREATING SYSTEMIC CHANGE

BY LAUREN AGORATUS, M.A.

Parent-to-Parent. Family-to-Family. In Our Own Voice. Support Groups. These are some of the terms used for supports from peers.

WHAT IS PEER SUPPORT?

Peer support is quite simply support given to an individual by someone who is, or has been in the same situation. This means someone who has "been there" or has "lived experience." Many state and national programs use this model to help parents in the areas of education, healthcare, mental health, child welfare, or family support.

HOW PEER SUPPORT HELPS PARENTS IN EDUCATION, HEALTHCARE, AND FAMILY SUPPORT

For education, Parent Training and Information Centers and Community Parent Resource Centers are parent-led organizations that help empower families to advocate for their children in general or special education. PTIs and CPRCs provide workshops and training. Their model is to do things with, not for, parents (see Resources).

The Center for Parent Information and Resources (CPIR) provides technical assistance for OSEP-funded Parent Centers to enhance their capacity to provide effective services for families of children with special needs and to work effectively with state agencies in improving services for infants, toddlers, children and youth with disabilities in their communities and states. In addition, RAISE (Resources for Advocacy, Independence, Self-determination and Employment) "works with the eight (8) Rehabilitation Service Administration (RSA)-funded Parent Training & Information Centers to develop and disseminate information and resources that increase their capacity to serve youth and young adults with disabilities and their families." So basically, the Parent Centers provide individual assistance to families, and CPIR and RAISE provide technical assistance to the Parent Centers to help them better serve families, youth and professionals.

Regarding healthcare, Family-to-Family Health Information Centers as well as Family Voices Affiliates (FVAOs) help parents. F2FHICs/FVAOs are family-led organizations that help parents navigate health care systems. They can help with appealing insurance denials, Medicaid, SSI, and condition specific resources.

Regarding children's mental health, Federation of Families for Children's Mental Health State Organizations and local chapters help parents, youth and professionals access behavioral health and other services. The 30 Statewide Family Networks are funded by the Substance Abuse and Mental Health Services Administration (SAMHSA) to provide support for families and youth to partner with professionals at all levels.

Under family support, Parent-to-Parent matches trained volunteers to families seeking emotional support and resources. The National Alliance on Mental Illness has local/state chapters offering workshops and support for children with challenging behaviors, including ADHD, Tourette's, and Autism Spectrum Disorder. Disability-Specific organizations do the same for a particular disability. Others, like Family Success Centers, or Parents Anonymous chapters, have a "strengthening families" approach.

FAMILY/PROFESSIONAL PARTNERSHIPS

Professional organizations have recognized the importance of the "family voice." Governor's Councils on Early Intervention, Special Education, and Developmental Disabilities include parents. Parents can serve on the Council itself or provide public comments on issues during meetings. Family Centered Care is "an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care professionals, patients, and families." The Medical Home model isn't a place but "an approach to providing comprehensive and high-quality primary care." Care must be:

- accessible
- family-centered
- continuous
- comprehensive
- coordinated
- compassionate
- culturally effective.

DONE THAT: Peer support is quite simply support given to an individual by someone who has "been there" or has "lived experience."

Even researchers are bringing families on board to advise on their project. CYSHCNet (Children and Youth with Special Health Care Needs Net) has families of children with special needs as advisors. Other programs may hold parent focus groups, or have families serve as reviewers for materials. In this way, the "end user" provides input during the process and materials are written in family-friendly languages with less professional jargon.

EMPOWERING SELF-ADVOCATES

Children with disabilities need to learn self-advocacy. Centers for Independent Living maximize potential and teach independent living skills. NAMI (National Alliance on Mental Illness) has In Our Own Voice that goes into schools to talk about lived experience with mental illness. Besides family support groups, they offer activities to children and support groups to teens/young adults as well.

DOES PEER SUPPORT WORK?

Research indicates that Peer Support is effective. Parents Anonymous uses "evidence-based Parents Anonymous® Programs

PEER POWER : EDUCATION, HEALTHCARE, MENTAL HEALTH, CHILD WELFARE AND FAMILY SUPPORT

PARENT TRAINING AND INFORMATION CENTERS
www.parentcenterhub.org/find-your-center

RAISE

RAISE
Resources for Advocacy, Independence, Self-determination and Employment
www.raisecenter.org

FAMILY VOICES®

FAMILY-TO-FAMILY/FAMILY VOICES
https://familyvoices.org

NFFCMH
National Federation of Families for Children's Mental Health

FEDERATION OF FAMILIES FOR CHILDREN'S MENTAL HEALTH
www.ffcmh.org/our-affiliates

PARENT TO PARENT USA

PARENT-TO-PARENT
www.p2pusa.org/parents

New Jersey Department of Children and Families

FAMILY SUCCESS CENTERS NJ
www.nj.gov/dcf/families/support/success

PARENTS ANONYMOUS®

PARENTS ANONYMOUS
www.nationalparenthelpline.org/find-support/state-resources

ecta
Early Childhood Technical Assistance Center

GOVERNOR'S COUNCILS – EARLY INTERVENTION
State Interagency Coordinating Council
https://ectacenter.org/topics/intercoord/intercoord.asp

IDEAs that Work

STATE SPECIAL EDUCATION ADVISORY PANELS
https://collab.osepideasthatwork.org/SAP/contacts

NACDD
National Association of Councils on Developmental Disabilities

DEVELOPMENTAL DISABILITY – COUNCIL ON DEVELOPMENTAL DISABILITIES
www.nacdd.org/councils

INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE

FAMILY CENTERED CARE
www.ipfcc.org/about/pfcc.html

National Resource Center
FOR PATIENT/FAMILY-CENTERED MEDICAL HOME
Formerly the National Center for Medical Home Implementation

MEDICAL HOME
https://medicalhomeinfo.aap.org/overview/Pages/Whatisthemedicalhome.aspx

CYSHCNET

CYSHCNET
Children/Youth with Special Health Care Needs
https://cyshcnet.org

ACL
Administration for Community Living

CENTERS FOR INDEPENDENT LIVING
https://acl.gov/programs/aging-and-disability-networks/centers-independent-living

nami
National Alliance on Mental Illness
Find Help. Find Hope.

NAMI
www.nami.org/findsupport

IN OUR OWN VOICE
www.nami.org/Support-Education/Mental-Health-Education/NAMI-In-Our-Own-Voice

by strengthening their families, advocating for better services and building resilient communities." NAMI utilizes many evidence-based programs on mental health.[1] SAMHSA (Substance Abuse and Mental Health Services Administration) also has a publication on the value of peer support.[2]

One of the common mottos in the disability community is "nothing about us without us." All stakeholders, including children with disabilities, are "in the trenches" and their voices must be heard to create systemic change.•

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

References

1. https://www.nami.org/About-Mental-Illness/Research/Research-on-NAMI-Programs
2. https://www.samhsa.gov/sites/default/files/programs_campaigns/brss_tacs/family-parent-caregiver-support-behavioral-health-2017.pdf

LIVE & ON-DEMAND VIRTUAL FITNESS CLASSES FOR ALL

BY LAUREN AGORATUS, M.A.

AN INNOVATIVE APPROACH TO FITNESS

COVID-19 has affected how people, including individuals with disabilities, can stay fit during the pandemic. During the pandemic, Spirit Club, a fitness club for people of all abilities, went virtual so everyone could stay well. Spirit Club has both live and on-demand classes. Classes are about an hour, and live classes are limited to 12 participants. These include personal training, as well as group classes. They offer a single-trainer view or multiple views, which adapts the activities.

VARIETY IS KEY

Classes change weekly. Besides offering both live and on-demand classes, Spirit Club offers various wellness activities. These include:

- Boxing
- General Fitness Workouts
- Zumba
- Balance
- High Intensity Interval Training
- Strength Building
- Yoga

OTHER ACTIVITIES

Wellness activities also include meditation besides yoga. Weekly health cooking recipes are offered. Special themes include workouts led by self-advocate and seven-time marathon runner Sam Smith. Classes are also offered in Spanish. Lastly, shorter classes of 30 minutes or less are offered to build up to the one-hour classes.

A CHAT WITH A PARTICIPANT

Going to the source, we asked a Spirit Club Participant for their thoughts:

Q: What do you think about Spirit Club?

A: It's a lot of fun!

Q: What do you like about it?

A: I like the exercises and different kinds.

Q: Is it easy to do? Why or why not?

A: Yes, because it's just like I do activities at my day program.

HOW TO JOIN & OTHER OPTIONS

Besides private pay, many organizations such as schools, faith-based, or disability specific have collaborated with Spirit Club to make it free to the population they serve. Although the pandemic closed gyms and brought fitness to a halt, Spirit Club offers a way for individuals with disabilities to stay well. Their motto is "Fitness for All"!

Another option that's free, once schools reopen, is Special Olympics. Special Olympics has sports teams and fitness facilities and offers Unified Sports with typical peers in schools.•

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

THAT'S THE SPIRIT : VIRTUAL FITNESS RESOURCES

SPIRIT CLUB

www.spirit-club.com

Information for Organizations

www.spirit-club.com/organizations

SPECIAL OLYMPICS UNIFIED SPORTS

www.specialolympics.org/our-work/sports/unified-sports

SPIRIT MOVES YOU: A multi-trainer view of a Spirit Club class.

IMAGE PROVIDED BY LAUREN AGORATUS/SPIRIT CLUB

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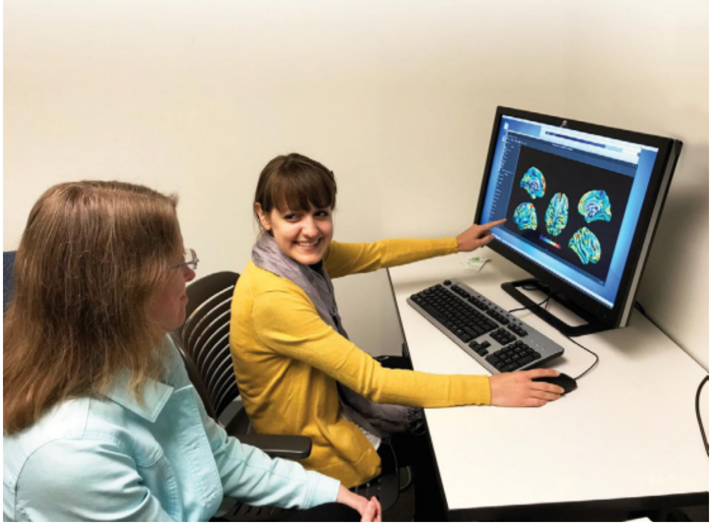

www.iesBrainResearch.org

(973) 726-6218 • iesBrainResearch@gmail.com

IES Brain Research Foundation thanks everyone who has participated & donated and wishes everyone a safe 2021.

A POOLED SPECIAL NEEDS TRUST MAY BE THE SOLUTION YOU'VE NEVER HEARD OF

BY MICHELLE K. WOLF

It's been a long busy day, taking care of yourself, your work or other family responsibilities, and your adult child with disabilities. After a relaxing hot shower, you puff up your pillow, lay down your head and close your eyes.

But instead of drifting off to dreamland, familiar questions race through your head: Who will take care of my child with disabilities when I am gone? How can I ensure there's enough money for him/her to obtain a high quality of life? Unfortunately, your dreams won't have the answers, but there's a solution you may never have heard of – a pooled special needs trusts, an affordable and easy way to set up 3rd party special-needs trusts with professional trustee services.

DOLLARS & SENSE

A SPECIAL SECTION

What is a Special Needs Trust?

Although many adults with disabilities are able to find paid employment, 82% of adults with disabilities (based on US Labor stats (**www.bls.gov/news.release/pdf/disabl.pdf**) are totally dependent on means-tested government benefits such as SSI and Medicaid. Eligibility for both of these essential programs limits single persons with disabilities to only $2,000 in assets at any one time (and married couples to $3,000). Although advocates have been calling for that asset ceiling to be raised to a more reasonable amount of at least $10,000, Congress hasn't yet changed that amount.

One way to legally save money beyond that $2,000 cap is tax-advantaged ABLE accounts; but they are limited to the maximum IRS gift tax exemption, currently $15,000, in a calendar year, so they won't work for larger asset amounts, such as from future life insurance payouts, or funds in a pension account

The other legal work-around is a 3rd special needs trust, usually created by parents or grandparents. A 3rd party special needs trust is a legal instrument that lets a person with a physical, mental, intellectual/developmental disability have access to private funds without potentially losing the benefits provided by public assistance programs. By law, it must be irrevocable. Money put in the trust doesn't count toward the purpose of qualifying for those crucial government benefits.

Unfortunately, these grantor-funded trusts are traditionally very expensive to create and manage. In fact, most professional trustees require a minimum of $500,000 in liquid assets, and annual and other fees can be in the thousands of dollars. Only the wealthiest have that kind of discretionary income, so what about the rest of us?

POOLING RESOURCES: Pooled trusts act as an "umbrella" over individual trust accounts, which are carefully managed in order to support persons with disabilities for as long as possible.

Pooled Special Needs Trusts

For those with less assets, an excellent solution is a Pooled Special Needs Trust, created by Congress in 1993. Using a Master trust document written by an expert attorney, pooled trusts act as an "umbrella" over individual trust accounts, which are carefully managed in order to support persons with disabilities for as long as possible. According to federal regulations, pooled special needs trusts must be administered by nonprofits. Clients enroll by signing a simple legal agreement called a "joinder" and pay a modest enrollment fee. Private funds are deposited into a sub-account for each participant and are pooled only for management and investment purposes. A bank or other financial services institution manages the investments, which must be invested in prudent investment options. Funds are disbursed by the pooled trust by pre-approval of their Trustee, and must follow relevant state and federal rules. Payments to third-parties only can be made by check, electronic fund transfers, or the use of a restricted-use VISA card issued by True Link Financial Services that can be customized for each user.

According to the Special Needs Alliance (SNA), a national organization comprised of attorneys committed to the practice of disability and public benefits law, "Since many financial institutions do not handle small SNTs, or charge fees that are not cost-effective for modest trusts, pooled trusts can give families access to highly skilled trustees."

There are pooled trusts available in every state, with a few national trusts that have separate Master Trusts for each state: www.specialneedsalliance.org/pooled-trust-directory/. Enrollment and annual fees vary widely, and you will need to check each agency's website or call for more details. Minimums also vary from a few thousand to $50,000.

If you are interested in more comprehensive services including person-centered planning and on-going case management, there's a subset of pooled trusts that are members of the National Planning Alliance: http://nationalplanalliance.org/

As a parent of a 26-year-old young man with I/DD, I first learned about pooled trusts in my professional work in the Los Angeles Jewish Federation, where I was surprised to find out that although every other major city had at least one pooled trust that could enroll children and adults with a variety of disabilities, Los Angeles, the second-largest city in the United States, didn't have one. Lawyers were referring clients to pooled trusts in Florida and other east coast cities, three time zones away.

Working with my boss, Sandy Samuels, then CEO of Bet Tzedek Legal Services, we were able to obtain seed grant funding from the Jewish Community Foundation for a Los Angeles-based pooled trust and we opened our doors in August 2016. We named it the Jewish Los Angeles Special Needs Trust & Services (JLA Trust for short) in honor of our deep connections in the Jewish community but we are open to all faiths, ethnicities and sexual/gender orientations, and our clients reflect the diversity that is Los Angeles County, with many Black, Latin, Middle-eastern and LBGTQ+ clients.

Our minimum for an active trust fund that can disburse funds is $20,000, and our average account is $41,000. Some question whether that amount of money can really make a difference in the life of someone with a disability, and the answer is a resounding yes.

For a client living in a group home, having extra money beyond SSI or SSDI means being able to buy new clothes, sneakers, bedroom furniture, a computer laptop or tablet, even annual trips to Disneyland or Las Vegas. Clients living independently can have money to buy household appliances or a flatscreen TV and also pay for their monthly internet and cable TV/streaming subscriptions. Even for elderly clients in assisted living or skilled nursing facilities, the extra funds can be used to private pay for personal aide/companion services, often crucial in Medicaid facilities which are often under-staffed. A large percentage of our clients use their trust funds to pay for long-overdue dental work, since it's so difficult to find a Medicaid dental provider, and many dental services aren't covered.

If you have been thinking about setting up a special needs trust, but not sure how you could afford the high costs of an attorney and on-going trustee costs, check out the pooled trust near you. Your bed is calling you to a more peaceful slumber. •

ABOUT THE AUTHOR:

Michelle K. Wolf is the Founding Executive Director of Jewish Los Angeles Special Needs Trust (JLA Trust) based in Los Angeles, CA.

TRUST THE PROCESS : MEET JULIE

We met Julie Weinberg when she was 50, living in a one-bedroom apartment in a suburb of Los Angeles. She is on the autism spectrum and has degenerative muscle disease, getting worse over time. In her earlier years, she had worked for a veterinarian, and was a sports fan who collected bobble heads. She was prone to long-winded conversations. Her dad, Michael, paid for her monthly rent and most of her living expenses. Her only monthly income was $895 from SSI (with a CA supplement).

Michael was a retired CPA whose wife had died many years ago. He had always planned that Karen, Julie's older sister, would take care of Julie after he passed, but when Karen turned 55, she told Michael that she was worn out from Julie's many phone calls and complaints about her pain, and didn't want to be in charge of Julie's finances. Michael then approached us. He had designated close to $200,000 for Julie, and established a 3rd party special needs pooled trust with our agency.

After he died, the money from his savings and investment accounts transferred over to Julie's trust account, and we began to pay for her rent and other expenses. The staff member assigned to Julie calls her at least once a month, and although Julie dearly misses her father, she is doing well and doesn't have to worry about paying her bills.

ARE FAMILY MONEY MESSAGES HOLDING YOU BACK?

BY ROB WRUBEL, CFP®

As parents and caregivers of people with disabilities, we are preparing for two generations. We have to fund our life today and into retirement while creating resources to support our family members after we are gone. Tackle those money messages.

A client was in the office recently and as we reviewed her retirement plan, she made one comment that stood out. She said, "My family always told me I'd never have any money." This client was on the verge of retirement, had significant equity in her house, more than six months of cash in an emergency fund and enough money to support her through retirement. She was in great financial shape and I could feel her pride and sense of satisfaction of her financial achievements.

The comment was unexpected. Here was a person who ran a large company, showed incredible intellectual and emotional intelligence and created assets that put her many multiples above the average for her age. And yet, one of her first thoughts was how shocked her family would be if she told them and how good it felt to prove them wrong.

My client had gotten this far by socking away lots of money later in her career. Her family was right in those first few decades of her working life – she hadn't made or saved enough. As she got further along, she understood that she needed to focus to be able to live the life of her choice and retire comfortably.

MIXED MESSAGES: "My client's family was right in those first few decades of her working life – she hadn't made or saved enough. As she got further along, she understood that she needed to focus to be able to live the life of her choice and retire comfortably.

The messages we hear growing, as in my client's case, up can make or break our financial lives, especially in the first decades of establishing our own households.

Many people I know heard positive money messages, along the lines of, "a penny saved is a penny earned," "pay yourself first," "you need a rainy-day fund" or "put 15% of your retirement away as soon as you start working and you will never have to worry about money." These families taught and reinforced good behavior. They encouraged their children to save, invest, be careful of debt, spend less than they earned and helped them take control of their financial lives.

Others heard messages that dissuaded them from taking action in their financial lives. Messages like the following often stop people from moving ahead: "No one in our family has ever had any money." "Only rich people have money." "The system is stacked against us." "You'll never get ahead." Or something equally discouraging.

Others learned by watching but making decisions without knowing the context. Yes, the stock market tumbled at the end of the tech bubble in the early part of the last decade. Yes, people lost their savings. On the other hand, those who stayed the course, had diversified portfolios and kept putting money away had the chance to create real wealth. If that was the basis of your decision to stay away from investing, it's time to rethink your money messages.

I've spoken to many who have had these negative messages drilled into their thinking from a young age and seen their families struggle with money without finding a way out.

Take a moment and write down or think through the money messages you carry around and where they came from. Are those messages serving you well or are they getting in the way of taking the steps needed to earn, save and invest more in your life? Without positive money messages, you won't be able to provide for your family member with a disability.

Where did these messages come from? Do you know others who have different experiences with money? Tony Robbins (yeah, that guy), said "Success leaves clues." Instead of taking advice and lessons from those who haven't handled money well, direct your efforts to finding people who have done well and ask what they did.

Change your financial course. By doing so, you can put yourself on track to enjoy your days more, knowing you will also have a secure future for yourself and your family member with special needs. •

ABOUT THE AUTHOR:

Rob Wrubel is a CFP who has a daughter with Down syndrome. He is recognized as a leading expert on financial planning for families with special needs members. Wrubel has written two books about financial planning and special needs families – *Financial Freedom for Special Needs Families: 9 Building Blocks to Reduce Stress, Preserve Benefits, Create a Fulfilling Future* and *Protect Your Family: Life Insurance Basics For Special Needs Planning* – and he has been published recently by Law360.com and The Good Men Project. Wrubel holds the Certified Financial Planning (CFP®) designation, the Accredited Investment Fiduciary® (AIF®) designation from Fi360, and the Accredited Estate Planner (AEP®) designation from the National Estate Planning Council.

FROM OUR FAMILIES... TO YOUR FAMILIES

MILITARY SECTION

MILITARY LIFE

PUZZLES AND CAMO

MILITARY CHILD CARE PROGRAMS

Choosing child care may be one of the most important decisions you'll make as a parent, and it can be hard to know where to start.

Rest assured, the Department of Defense provides military families with a variety of quality, affordable child care options.he Department of Defense is committed to meeting the growing and diverse child care needs of military families, and takes great pride in the quality of services provided to children on and off installations worldwide. While services may vary by location, the standards and quality of services are consistent and meet established regulations. Learn more about military child care program options below.

CHILD DEVELOPMENT CENTERS

Child development centers, or CDCs, are located on installations and generally offer care for infants through preschool age children. Child care is available Monday through Friday, during standard work hours (e.g., 6 a.m. – 6 p.m.) with some locations offering extended hours. CDC programs provide full-day and part-day care. Centers vary in size and larger installations may operate multiple facilities. CDC programs have Department of Defense certification, and accreditation from a national accrediting body such as the National Association for the Education of Young Children.

FAMILY CHILD CARE

Family child care providers are certified professionals who provide child care for infants through school age children in their homes, located either on or off an installation. FCC providers typically offer a flexible schedule to support parents with a variety of care needs, including full-day, part-day, and school year care, summer camp, and in some cases, 24/7 and extended care. Regulations limit the number of children who receive care at any one time to no more than six children under age eight, and no more than three children when all children are under age two. Family child care providers must be certified by the installation to operate. Individual providers may voluntarily seek national accreditation from the National Association for Family Child Care and receive local support, training, and materials to accomplish this goal.

SCHOOL AGED CARE

School-age care, or SAC, programs provide care to children in kindergarten through sixth grade. Care is offered before and after school, during non-school days and summer vacations. SAC programs may take place in Department of Defense youth centers, child development centers, or other suitable facilities. All programs have Department of Defense certification, and accreditation by a national accrediting body such as the Council on Accreditation.

REQUESTING CHILD CARE

- MilitaryChildCare.com is a Department of Defense website that helps families in any service branch find and request military-operated child care anywhere in the world. Families can search for full- and part-time care in the CDC, FCC and SAC programs outlined above.
- If your child has special needs, your service will work closely with you to find the best placement for your child. You can contact your installation Exceptional Family Member Program (**https://installations.militaryonesource.mil/?looking-for-a=program/program-service=29/focus=program**) to learn about options for your family. For more information, visit the Military OneSource Exceptional Family Member Program Family Support page at **www.militaryonesource.mil/family-relationships/special-needs/exceptional-family-member/exceptional-family-member-program-family-support**

HOURLY CHILD CARE SERVICE

In addition to child care programs available through MilitaryChildCare.com, the Department of Defense is proud to offer an expanded child care service to help meet the growing and diverse needs of military families. Through Military OneSource, parents can now access a nationally recognized caregiver database to search for hourly, flexible and on-demand child care.

The online caregiver service lets you:

- Search for care that fits your own needs and criteria
- Find potential care providers
- Check references
- Review background checks
- Interview, hire and pay providers on your terms

Use your Military OneSource account to set up free access to the online child care service. Log in to your existing account (**https://auth.militaryonesource.mil/MOS/f?p=UIS:CONSENT:0::::AID:1005**) or create an account to get a unique subscription code (**https://auth.militaryonesource.mil/MOS/f?p=UIS:CONSENT:209231563125720::::AID:1005**) and establish your child care service account.

For more information about the online caregiver search service, and to register, visit Military OneSource Expanded Hourly Child Care Options at **www.militaryonesource.mil/family-relationships/parenting-and-children/military-childcare-services**

FINDING CHILD CARE THAT IS RIGHT FOR YOU

If this is your first time arranging child care and you're feeling overwhelmed, Child Care Aware of America offers lots of helpful information for families. Resources include these downloadable checklists with questions to help you compare different options and make the right child care decision for your family:

- Child Care Center Checklist: **www.childcareaware.org/families/choosing-quality-child-care/selecting-child-care-program/child-care-center-checklist/**
- Family Child Care Home Checklist: **www.childcareaware.org/families/choosing-quality-child-care/selecting-child-care-program/family-child-care-home-checklist/**
- Preschool Program Checklist: **www.childcareaware.org/families/choosing-quality-child-care/selecting-child-care-program/preschool-program-checklist/**
- School-Age Child Care Program Checklist; **www.childcareaware.org/families/choosing-quality-child-care/selecting-child-care-program/school-age-program-checklist/**

Child Care Aware of America manages several programs for the military and you may be eligible for fee assistance (**www.childcareaware.org/fee-assistancerespite**).

If you have questions about child care, parenting or military life in general, reach out to Military OneSource. Consultants are available 24/7/365 to answer questions and connect you with resources to help your family thrive. Call 800-342-9647.

– Military OneSource

HOURLY CHILD CARE? YOU'VE GOT IT.

Through Military OneSource, parents now have free access to a national database to search for hourly, flexible and on-demand child care.

www.militaryonesource.mil/family-relationships/parenting-and-children

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EDUCATION DIRECTORY FOR CHILDREN WITH SPECIAL NEEDS

The Education Directory for Children With Special Needs (**https://efmpeducationdirectory.militaryonesource.mil**) is a web-based tool that helps military families with special needs make informed decisions about education and early intervention services available on or near installations within the 50 states and the District of Columbia.

The directory has two components:

- Early Intervention Directory (Birth-3) **https://efmpeducationdirectory.militaryonesource.mil/early-intervention-directory**
- School-Age Directory (3-21) **https://efmpeducationdirectory.militaryonesource.mil/school-age-directory**

Both sections of the directory offer the following information (specific to the needs of each age group):

- Services, contacts and resources each state offers
- Profiles and contacts for service providers and school districts

- Links to tools for a smooth transition
- Links to national trends and resources
- Definitions of related terms

Use the Education Directory for Children With Special Needs to help you prepare for the services your family needs.

Visit the Directory at **https://efmpeducationdirectory.militaryonesource.mil**

– Military OneSource

TRICARE

COVID-19 VACCINATION

GET THE FACTS

GETTING THE COVID-19 VACCINE AT CIVILIAN PHARMACIES

YOU CAN GET THE COVID-19 VACCINE FROM ANY CIVILIAN PHARMACY AT NO CHARGE, EVEN NON-NETWORK PHARMACIES, BUT HERE ARE SOME THINGS TO KEEP IN MIND.

NETWORK PHARMACIES

- You can get the vaccine at no charge from any TRICARE network pharmacy.
- Contact your network pharmacy first to see when you can get your vaccine and what processes they may have in place.
- **To find a network pharmacy, visit:** https://militaryrx.express-scripts.com/find-pharmacy

NON-NETWORK PHARMACIES

- You can get the vaccine at no charge from any non-network pharmacy – the pharmacy is not allowed to bill you.
- Non-network pharmacy coverage rules apply for medications (non-vaccines).
- If you get anything other than the COVID-19 vaccine, you're responsible for that cost, based on your TRICARE plan.
- **For more information, visit:** www.tricare.mil/NonNetworkPharmacy

Remember, COVID-19 vaccines are being administered based on CDC and DOD priorities. Be sure to call first to see if it's your time to get the vaccine.

ACTIVE DUTY SERVICE MEMBERS:

If you get your COVID-19 vaccine at a civilian pharmacy, follow your Service policy guidance for recording the vaccine in your health record.

To learn more, visit: www.tricare.mil/COVIDVaccine

As of Feb. 5, 2021

TRICARE®

SPRING CLEAN YOUR EFMP SCOR

Set a date this spring to clean up and organize your Exceptional Family Member Program Special Care Organizational Records so your family's medical and educational records are updated and accurate.

This will be especially important if coronavirus precautions affected your plans and resources. If you're creating your first EFMP SCOR, spring into action by capturing and organizing your information in a single location using the different sections to accommodate your specific needs.

REFRESH YOUR EFMP SCOR

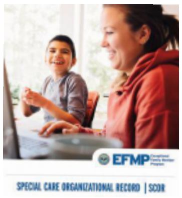
Keep the following tips in mind as you update your EFMP SCOR (www.militaryonesource.mil/leaders-service-providers/efmp-special-needs/special-care-organizational-records):

- Download clean copies of forms, new pictures and covers. Note that the forms are fillable using your keyboard, so you can update information, print and insert into your current EFMP SCOR.
- Review the In Case of Emergency section and make sure the information is correct and up to date.
- Update all of the records as needed with your current health care providers, school and other contacts. You should also update the record each time you PCS, change doctors, schools, EFMP contacts, outside contacts, etc.
- Choose only the important information and documents to keep in your EFMP SCOR. Create a separate file to store less critical or older information. Don't clutter your SCOR with excess paperwork. Throw away paperwork or items you don't need.
- Consider keeping or adding these items to your EFMP SCOR:
  - *Medical treatments that did or did not work*
  - *Time-stamped notes on who you spoke to and what was said*
  - *Official education reports on plans and progress*
  - *A hard copy of EFMP & Me checklists (*https://efmpandme.militaryonesource.mil*) you might be working on*

SET UP A NEW EFMP SCOR

If this is your first EFMP SCOR, these tips can help you get started.

- Download and complete forms including routines, likes and dislikes, contact information, emergency action plan, etc., so you will have all the information you need in one place. You can also order a hard copy EFMP SCOR if you prefer.
- Save an updated copy of your SCOR on a thumbdrive so you can take it with you in an emergency.
- Collect and add information to the EFMP SCOR. These may include medical documents, including paperwork from recent doctor visits, immunization records, recent hospital stays, test results, etc. Individualized Education Programs for children and notes can also be added. Make sure to store less important information in a separate file to avoid cluttering your EFMP SCOR.
- Keep a separate EFMP SCOR with individual information for each family member with special needs. This will help keep everything organized and will also be helpful when you update your EFMP enrollment.
- Remember that your EFMP SCOR doesn't replace official medical records and is not legally binding. It also includes personal information so be sure to keep it in a safe place.
- Review the EFMP video (https://millifelearning.militaryonesource.mil/f?p=332:8) on Special Care Organization Record on MilLife Learning.
- Consider including a copy of your EFMP & Me checklist (https://efmpandme.militaryonesource.mil) in your EFMP SCOR and track progress.



DOWNLOAD YOUR EFMP SCOR

The Special Care Organizational Record is intended to help track and organize information in one central location. Using the SCOR will make it easier for someone else to step into the role of caregiver, if that is ever needed.

www.militaryonesource.mil/leaders-service-providers/efmp-special-needs/special-care-organizational-records

Reach out to your nearest installation EFMP Family Support provider or a Military OneSource special needs consultant if you need assistance or have questions about how to set up or manage your SCOR. Schedule appointments 24/7 by live chat or calling 800-342-9647.

– Military OneSource

PUZZLES & CAMO SHELLY HUHTANEN

Hope for Tomorrow

The Exceptional Family Member Program was established in 1979 to assist families who serve our country. With the help of advocates for military families raising children with disabilities, voices describing hardships these families face have steadily grown louder and louder.

GOLDEN ANNIVERSARY
50 YEARS OF EP
1971 – 2021

The military has always been a microcosm of our nation. Our military families have similar needs and desires as civilian families. The difference is that people in the military very seldom have a choice in where they reside and how frequently they need to move, affecting the length of time they are living at a duty station. It is common for a military family not to have a preferred choice in the best school available for their child, and that can lead to added stress to the family and to that child with the disability. While experiencing these hurdles, their soldier may be working long hours, gone for weeks at a time for training, or months for a deployment. Our military experiences similar struggles and triumphs, just like families in the civilian world, but do so while carrying a very heavy load of uncertainty. Similar to civilian families with members with disabilities, our military families strive to learn from the past and continue to push forward in the hopes of a better future for our loved ones with disabilities.

PROGRESS MADE: There is more that needs to be done to ensure our families have the support they need, but with advocates like EFMP, there has been a shift.

I remember sitting on my husband's grandmother's back porch on a swing in Corvallis, MT. She was a teacher in the 1960's and 1970's and spoke fondly of her profession. We were talking about Broden's diagnosis of autism and pontificating about the journey that lay ahead for our family. She said, "I taught for 20 years and I can't remember one child in my class who had autism or a significant disability." She told me that there were children in her class that would need more assistance than others, but she could not recall a child in her class over those 20 years that had a disability. In 1975, the FAPE (Free Appropriate Public Education) law was passed and it was the spark that ignited change for children with disabilities. My husband's grandma realized on her back porch that day that it was not because children like Broden didn't exist, it was because children like Broden did not get to have the opportunity to have her as a teacher.

Times have changed, but advocacy is still a necessity to ensure our children are provided opportunities and appropriate support they need to live and thrive.

Although FAPE was passed in 1975, IDEA (Individuals with Disabilities Education Act) was not passed until 1997. The ADA (Americans with Disabilities Act) was finally passed in 1990, prohibiting discrimination against people with disabilities. While the movement towards giving people with disabilities a voice has made a difference, there has also been a movement in the military community.

Similar to the civilian world, children with disabilities did not have a voice in the military. With every move, families either did not receive services or were told to accept whatever was minimally provided. EFMP, the Exceptional Family Member Program, was established in 1979 to assist these families who serve our country. With the help of advocates for military families raising children with disabilities, voices describing hardships these families face have steadily grown louder and louder. The struggle is still real and there is so much more that needs to be done to ensure our families have the support they need, but there has been a shift. We have a seat at the table. Our children are no longer held in the shadows, but have been brought into the light. Years ago, when there may have been shame or secrecy, those days are over.

I remember years ago, at an elementary school in Fort Hood, being told they make a point to "keep the special needs kids away from the other children in the school." That moment still saddens me and reminds me that the need for advocacy for our military children will always be needed, but my heart remains open and I stay hopeful. I'm hopeful when I remember positive experiences, such as my son with autism standing with us at my husband's promotion ceremony and pinning his new rank on his father's chest in front of an auditorium of family and friends.

As I watch families outside of our military gate advocate for better education and health care for their family members with disabilities, our military members are advocating for their families as well. Each installation involves new hurdles to jump or new walls to climb, but we continue to push through those barriers, just like our fellow civilians outside our military gate. For our military, it is imperative that leadership stays engaged and finds the courage to solve hard problems.

Over the next 50 years, my hope is that our community continues to strive for better quality of life for people with disabilities in the military. The struggles that people with disabilities face in our military community need to continue to be in the conversation. Leaders need to be focused on holding schools in their local communities accountable by ensuring trained special education advocates are available for military families because a strong IEP that is enforced matters.

> "Over the next 50 years, my hope is that our community continues to strive for better quality of life for people with disabilities in the military. The struggles need to continue to be in the conversation."

Continuity of care for our families matters. In the next 50 years, it should not matter which branch of the military you serve in to determine the quality of support you receive. An Army family should receive access to a trained special education advocate, just like a Marine family. A service member should never question if his or her career progression is in jeopardy because they are only living at installations that are able to support their family member's needs. Military families who have members with disabilities will continue to matter. They always have. •

PUZZLES & CAMO

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

ADAPTIVE/SPECIAL NEEDS BEDS

KAYSERBETTEN

P: 800-574-7880
E: ruthann@kayserbettenus.com
W: www.kayserbettenus.com
Designed to allow the child to be part of the surroundings while being safe and secure in their bed.

BENCHCRAFTED FURNITURE

MAINE WOODWORKS

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E: info@mainewoodworks.org
P: 207-887-1989
A nonprofit organization that supports individuals with disabilities, Maine Woodworks employs an integrated workforce, made up of people both with and without disabilities.

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Coronavirus Disease 2019

COVID-19

What you need to know to keep your family **safe and healthy.**

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According to the CDC, the virus is thought to spread mainly from person-to-person. It's important to stay "two carts apart" or "one car far" from others when in public areas to reduce the spread of COVID-19.

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www.tricare.mil/coronavirus

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