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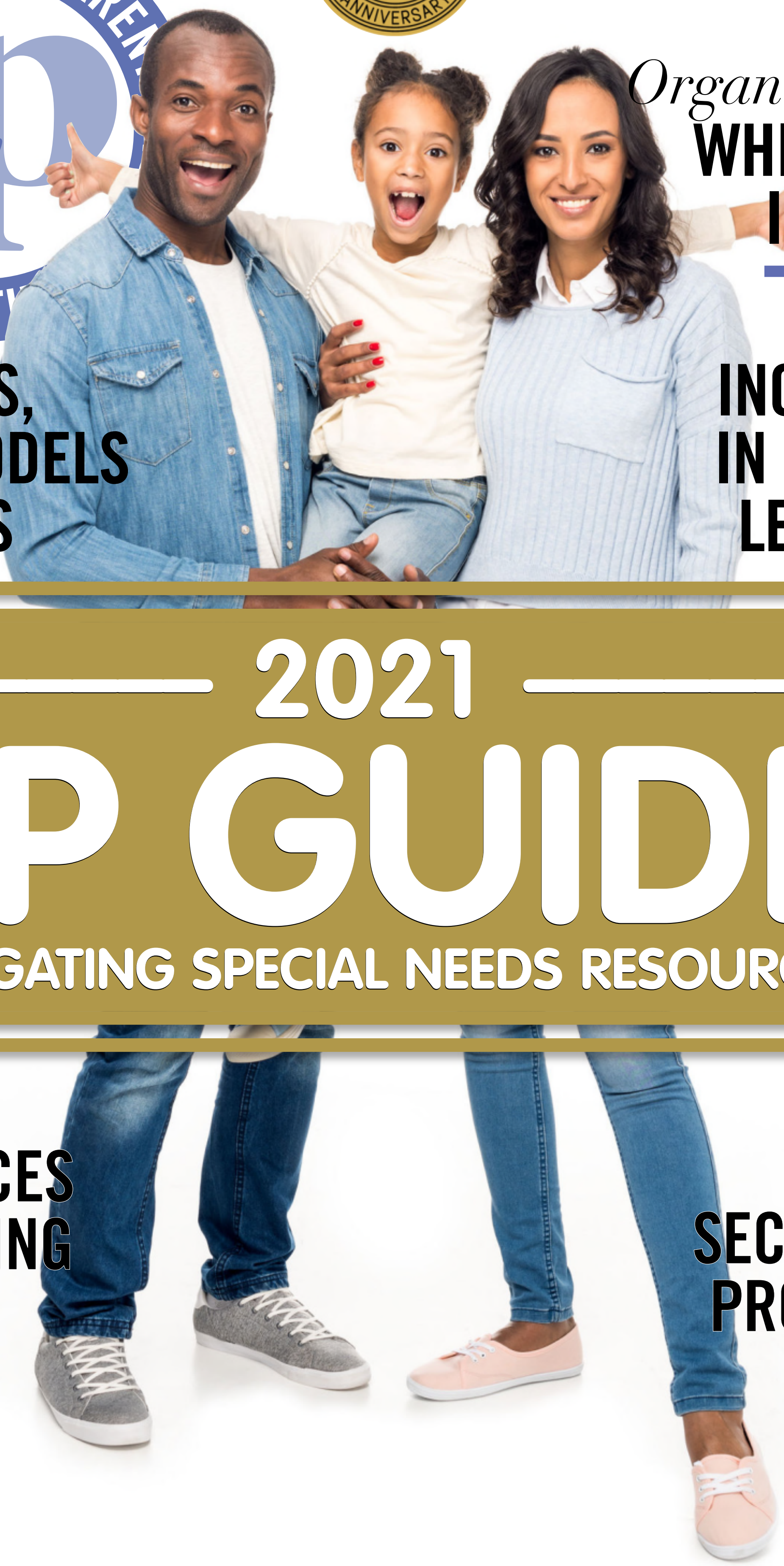

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2021 EP GUIDE

ON OUR COVER

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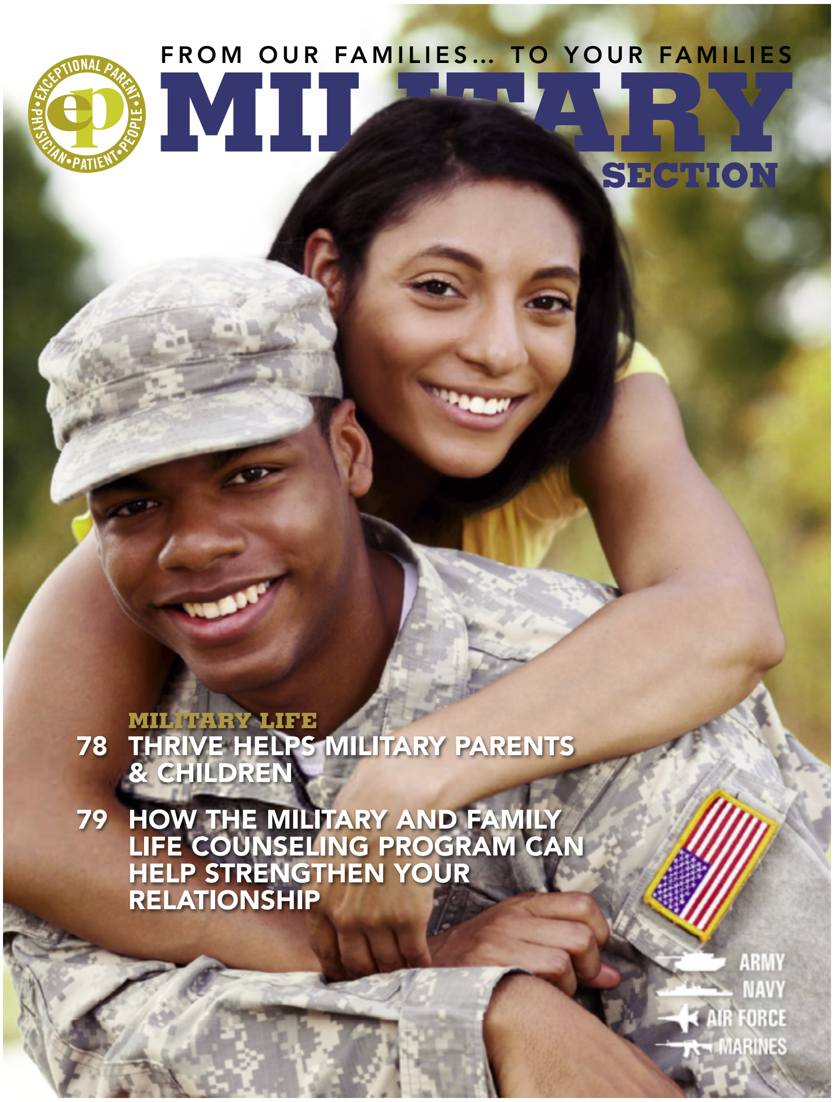

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Information and Support for the Special Needs Community

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

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

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

It Was a Dark and Stormy Night

Exceptional Parent Magazine has evolved. What was once exclusively dedicated to parents is now universally read by all the stakeholders in the disability community.

“It was a dark and stormy night.”

That phrase was frequently used by cartoonist Charles M. Schulz in the popular comic strip Peanuts. Ever since I first read it, I wanted to open an article with it. Schulz often depicted Snoopy as an aspiring author sitting on top of his dog house, typing out: “It was a dark and stormy night.” Now that I have done that, I guess it’s another check off my bucket list.

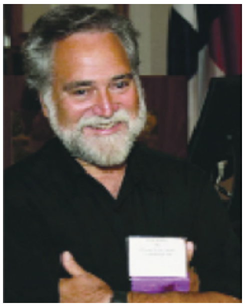
In actuality, the phrase predated Peanuts. It stands as the universal cry for bad writing and it comes from the first phrase of the opening sentence of English novelist Edward Bulwer-Lytton’s 1830 novel Paul Clifford. In its entirety, “It was a dark and stormy night; the rain fell in torrents – except at occasional intervals, when it was checked by a violent gust of wind which swept up the streets (for it is in London that our scene lies), rattling along the housetops, and fiercely agitating the scanty flame of the lamps that struggled against the darkness.”

THE WORLD FAMOUS AUTHOR: In one strip, Linus says Snoopy’s stories all begin the same way, and tells the beagle he should change that. Snoopy responds by writing, “It was a stormy and dark night.”

Writer’s Digest described the sentence as “the literary posterchild for bad story starters.” On the other hand, the American Book Review ranked it as No. 22 on its “Best first lines from novels” list. So much for universal agreement on anything.

“It was a dark and stormy night” describes most nights, and most days for parents of children with special health care needs at the dawn of the disability rights movement.

In the early 1970’s, the landscape for children with disabilities (adults with disabilities were invisible and off anyone’s radar) and their families was bleak, uninviting, and inhospitable. While there were pioneering advocacy efforts prior to that, most families opted to send their children to institutions or keep them isolated at home. Credit has to be given to those progressive organizations that were formed to give a voice to those desperate families. United Cerebral Palsy in 1949, The Arc in 1950, The National Association for Down Syndrome in 1960, and Special Olympics in 1968 were beacons of hope and models for families that had hoped for opportunities for their children to be respected, welcomed, and included in the community.



But, the reality was in the early 1970’s, the rights of people with disabilities were not actively promoted or protected by the Federal government. It wasn’t until 1973 that the landmark Section 504 of the Rehabilitation Act was enacted. The Americans with Disabilities Act did not become law until 1990, and the Olmstead Act was not passed until 1999. Rosa’s Law, which addressed the need for appropriate descriptive language, did not appear until 2009.

Part of the reason for the “dark and stormy nights” experienced by families in the early 1970’s was the lack of resources for information, places to go for answers to their questions, a network to learn from others and a trusted and supportive “mother ship.”

That changed in 1971. It was certainly a dynamic year on all accounts. The year had three partial solar eclipses and two total lunar eclipses. It was the year they banned cigarette advertising on radio and television. Apollo 14 landed on the moon. Rolls Royce went bankrupt. Satchel Paige became the first Negro League player to be voted into the Baseball Hall of Fame from the Negro League. The United Kingdom switched to decimal currency. Evel Knievel set a world record and jumped over 19 cars on a motorcycle. The *Ed Sullivan Show* aired its final episode. Starbucks, the mega coffeehouse power, was founded. President Nixon declared the U.S. War on Drugs. Federal Express was a start-up company. The hit movie, *Willy Wonka & the Chocolate Factory,* hit the theatres. Two new magazines were started: *Ms. Magazine* and *Playgirl.* The voting age was lowered from 21 to 18. Walt Disney World opened in Orlando, Florida. The U.S. dollar was devalued for the second time in history. Hundreds of thousands of Americans protested the war in Viet Nam. The start of the digital age took place with the invention of the microprocessor… And three Boston psychologists saw an opportunity.

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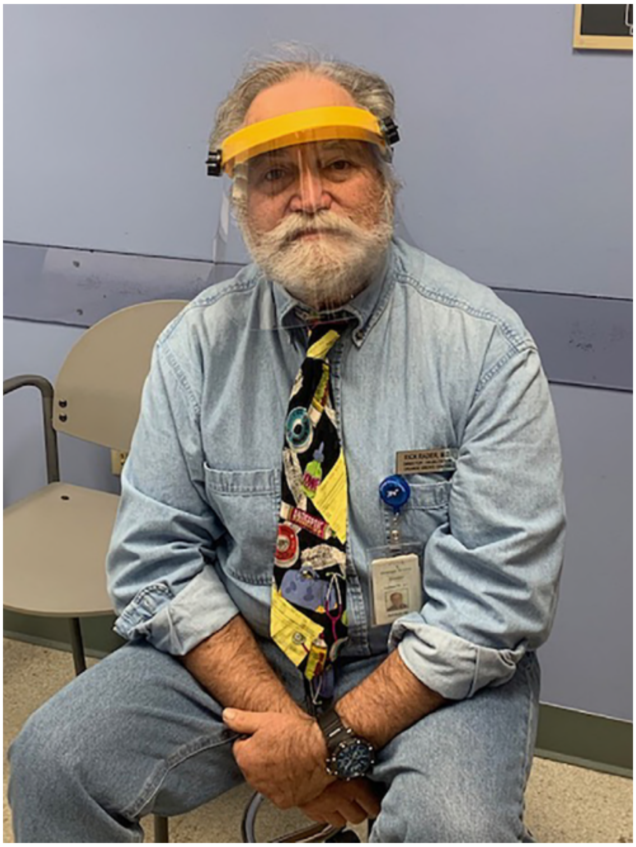

TIES THAT BIND: *(Left)* Dr. Rader appears on the August 1994 cover of EP alongside Orange Grove Center patient Kelly Bankston; *(Above)* A recent photo featuring the same necktie from his extensive collection. While EP is celebrating its 50th anniversary; Dr Rader is celebrating more than 25 years at *EP Magazine.*

In 1971, the dark and stormy nights began to fade. The three founding editors of *Exceptional Parent Magazine* found a mission, "to provide practical guidance for the parents of exceptional children."

Dr. Maxwell J. Schleifer, Dr. Lewis B. Klebanoff, and Dr. Stanley D. Klein described their venture:

> *"This is* The Exceptional Parent… *a magazine created to deal with the issues many of you have been struggling with for long and so patiently – the frustrations, disappointments and yes, the triumphs of raising a child with a disability.*
>
> *For many years, we, the editors of* Exceptional Parent, *in our clinical and administrative work with disabled children and their families, have experienced similar frustrations, disappointments, and triumphs. At the same time, each of us has attempted to share our experiences at parent and professional meetings, on radio and television, and in published reports.*
>
> *More than two years ago,* The Exceptional Parent *was conceived as a forum for the mutual sharing of the acquired knowledge of both parents and professionals. Their enthusiasm encouraged us in our knowledge.*
>
> *To the best of our knowledge, a magazine of this nature has never been attempted. From our struggles with the first issue, we are aware that we need your help. We need your suggestions, criticisms, and contributions, where you are as a parent, a professional, a person with a disability – or perhaps, all three. We believe that we need to share with each other, to learn from each other, and to grow together."*

State of Editorial Purpose: *"Child-rearing is a vital and difficult task, unrecognized as such and unsung, perhaps, because it is so universal. Even more vital and much more difficulty is the task of raising a child with a disability. Much progress is being made in the understanding and habilitation of those afflicted with all of the major disabling conditions of childhood. Sadly lacking in these efforts is any coordinated system of translating these findings into meaningful form for parents. Practical, human, daily questions as well as issues of long-range, planning, care and financing are what you will find in the pages of The Exceptional Parent. Technical information stripped of professional jargon and practical advice on day-to-day care will share these pages with many special features, including ideas from our readers. Our goal is to help you to share with us the view that the child is our main concern, that disability, however severe, is secondary."*

PHOTO BY DENNIS WILKES

In 1994, I read a seductive ad in the *Journal of the American Medical Association*. An unidentified community agency was interested in supporting a physician to help forge the future of healthcare for people with intellectual and developmental disabilities. Like most (all) physicians at the time, I did not receive any formal training in treating patients with disabilities. We saw them in our clinics, but not because of their disabilities, but as a consequence of them (deferred care, misdiagnosis, diagnostic overshadowing, and indifference). It was intriguing, challenging and attractive.

While I was clueless about the field (or what passed for the "field" at the time) I had a track record in stress medicine, medical innovation and new medical initiatives (pharmacoeconomics, social medicine, medical informatics, physician education). I couldn't resist, and luckily, neither could they. I found myself as the new Director of the Morton J. Kent Habilitation Center at the Orange Grove Center in Chattanooga; established in 1953 by parents who refused to accept the advice of the day, "Send him to an institution and concentrate on the normal ones." They didn't and created a celebrated and progressive community for people with intellectual disabilities, their families, and others who watched and imagined its potential for replication.

My role was like something from *Star Trek* – "go out into the world and beg, borrow, steal or create new ways to improve

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

In no special order (and with sole responsibility for anticipated omissions), we have seen the following "big ticket items" that have brought new heights to people, families and communities with disabilities:

Universal newborn screening • Recognition of people aging with disabilities • Evolution of the medical model to the social model • The rise of the Direct Support Professional • The Orphan Drug Act • National Center on Birth Defects and Developmental Disabilities • Surgeon General's Conference of Health Disparities of People with Mental Retardation • Special Olympics Healthy Athletes Programs • The American Academy of Developmental Medicine and Dentistry • Recognition of autism and its growth • Dementia and Down syndrome • National Council on Disability • Self advocates movement • Family Voices • Recognition of mitochondrial disease • Financial Planning • Project DOCC • Katie Beckett • "Voice of the Retarded" • Boy Scout Merit Badge on Disability Awareness • President's Committee on People with Intellectual Disabilities • National Leadership Consortium on Developmental Disabilities • Individual Education Plan • ANCOR • Developmental Disabilities Nurses Association • National Association on Dual Diagnosis • Special Care Dental Association • Montreal Declaration • Willowbrook State School scandal • Social Role Valorization • Normalization • Ableism • University Centers of Excellence in Developmental Disabilities • American Association on Health and Disability • Golisano Foundation • WISH Foundation • Settings Rule • Self-determination • Supported Living • Assistive technology • Sensory Processing Disorder • Unfunded mandates • Hyperbaric oxygen therapy • Inclusion • Mainstream education • Council for Exceptional Children • Autism Speaks • UN Declaration for the Rights of People with Disabilities • Supported Decision Making • Autism Self-Advocates Network • Applied Behavioral Analysis • Christmas in Purgatory • Organ Transplants in People with Intellectual Disabilities • Americans with Disabilities Act • Olmstead Act • Cochlear implants • Crisis Intervention Training for Law Enforcement • Implantable medical devices • Not Dead Yet • Mothers From Hell • Recognition of U.S. Military Exceptional Family programs • World Congress on Disability • Human Genome Project • The Fetus as Patient • Unified Sports of Special Olympics • Brain Banks • Simulated patients with disabilities • Positive Exposure • National Task Group on Intellectual Disabilities and Dementia Practice • Multi-Sensory Environments • American Academy of Developmental Medicine • Project Accessible Oral Health • Physician Decision Making • End-of-Life Care for People with Disabilities • Desensitization • Retirement • Sex Education for People with Disabilities • Genetic Testing • HIPPA • Adaptive Sports • Recognition of Fragile X • The Arc of the United States • AUCD • College Opportunities for Students with Disabilities • Simon Foundation for Continence • Religion, Spirituality for People with Disabilities • Positive Behavioral Supports • Robotic Education in Autism • "Meaningful day" • Active Treatment • End of Sub-Minimal Wages • Habilitation Model • Sib Shops • American Association on Intellectual and Developmental Disabilities • Female Health Initiatives • Preventive Health Strategies for People with Disabilities • Programs to Document and Teach About Eugenics • Changing Faces • The rise of single syndrome support groups • College courses on Stigma • State Councils on Developmental Disabilities • The "Medical Narrative" • Pet therapy • Equine assisted therapy • Service animals • Practice Without Pressure • Music Therapy • Art Therapy • Dance Therapy • Play Therapy • Electronic Communication Devices • Medically Underserved Population Designation • Mobility Devices • Accessible Transportation • SMART Homes • Grief counseling for People with Disabilities • Transitions • The Patient Experience • Grandparents as Caregivers • Micro-enterprises • Inclusion International • Different Brains

And, to the other countless groups, movements, innovations, challenges, initiatives, programs and best practices which we have had both the pleasure and opportunity to report on over the past 50 years... thank you for allowing us the privilege of covering you in *Exceptional Parent Magazine.*

the lives of people with intellectual and developmental disabilities." The stipulations of my contract were indeed novel. I asked for a parking spot (being from New York, this was quite the perk), permission to wear jeans, and to act as a free-range chicken for a year to learn about the field, the culture of Orange Grove, needs, resources, challenges, syndromes, and how key champions in the field viewed obstacles, innovation, and sustainability. I had no time to waste and realized I needed to learn some key terms, phrases and history. I took advantage of attending a conference at the University of Wisconsin and signed up for as many sessions as I could. I was overwhelmed, intimidated, and relieved that my attendee badge announced that this was my first time at the conference. I probably didn't need the badge to announce my virginity; my bewildered expression was a dead giveaway.

On the afternoon of the last day, I attended a session conducted by Dr. Klein. During the Q & A session, I had posed several questions that announced I was both a novice and thirsty to know more. I insisted on responding to his answers with the question, "But why can't that happen?" At the end of the session, we sat down for a cup of coffee and I explained my new position and my excitement. I shared with him my latest venture of recruiting individuals with intellectual disabilities as "simulated patients" and having medical students and residents learn about their "conditions," their lives and their humanity. It was the first time this was ever attempted and Dr. Klein invited me to write an article about the project. He had me at "write."

Several months later, I was scheduled to present the results of my first year to the Orange Grove Advisory Board that was assigned to evaluate my contributions, my potential, and any accomplishments. They were true to their word of giving me unbridled free range for a year (it was a leap of faith for both of us) to get my footing in this new initiative. The day before the meeting, I received a package from *Exceptional Parent Magazine.* It was several copies of the latest issue. The cover story was my article of a "new twist to playing doctor" *(See page 5).* My debut of introducing "simulated patients with intellectual disabilities" at Grand Rounds at the Chattanooga Branch of University of Tennessee College of Medicine-Erlanger Hospital was a huge success. It resulted in the adoption of a curriculum for fourth year medical students during their rotations at Erlanger Hospital.

> "The year 2021 marks the 50th Anniversary of *Exceptional Parent Magazine.* It is the oldest, most respected, and continuously published resource for the disability community."

At the meeting with my Advisory Board, they posed the expected question, "Well it's been a year, why should we keep you?" I reached into my book bag and handed each of them a copy of the new issue of *Exceptional Parent Magazine* (with my cover story and picture). Along with the magazine were a stack of letters from prestigious medical schools interested in replicating the program. I started to publish articles in *Exceptional Parent Magazine* and, in 2000, following the passing of Dr. Maxwell J. Schleifer, was appointed as the Editor in chief, a position I continue to be both humbled and inspired to hold.

The year 2021 marks the 50th Anniversary of *Exceptional Parent Magazine* (now called *EP Magazine* for short). It is the oldest, most respected, and continuously published resource for the disability community. The magazine has "grown up" with the disability rights movement and has chronicled the progress, the luminaries and the achievements of the grass roots organizations, the mom-and-pop start-ups, and the inclusion of people with disabilities.

The past half century has seen remarkable progress in medical achievement, legislation, technology, and human potential.

Exceptional Parent Magazine has supported and reported on the key events, milestones and "mountain moving" movements that have reshaped the world for the disability community.

E*xceptional Parent Magazine* has evolved. What was once exclusively dedicated to parents is now universally read by all the stakeholders in the disability community. Parents started to tear out articles from the magazine and brought them to their appointments with doctors; they slapped them down on the desks and asked (often with tears in their eyes), "Why didn't you tell me about this?" This was cutting-edge information and often, even the doctors were unaware of these new programs, new treatments, and new potentials. They began to subscribe to *Exceptional Parent Magazine*, they began to submit articles, and began to provide those to their families. No longer primarily a magazine for "parents" the P began to reflect the physicians, the providers, the professionals, the partners… and even the payers.

Several years ago, I was reminded of just how significant *EP Magazine* was to countless families. A woman called me and introduced herself. She was a physical therapist and mother of a son with cerebral palsy. She recently retired from her practice (specializing in children with disabilities); her son had passed away in his early 40's but she continued to subscribe to EP for another 20 years. She wanted to donate her entire collection of *EP Magazine,* over 400 issues, and said that while *EP Magazine* was a great source for "new" information… every day, the parent of a child with newly–diagnosed, disabling conditions becomes an "exceptional parent." And much of the information is timeless, "new" to "new" parents, and worth their weight in reassuring them that they are not alone.

Here's to another 50 years of insuring that exceptional parents do not have to face even one "dark and stormy night." •

ANCORA IMPARO

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

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

WHAT'S HAPPENING

EP WELCOMES TWO "GAME CHANGERS" TO THE EDITORIAL ADVISORY BOARD

When we finally and truly become the United States of Inclusion, the portrait on the new hundred-dollar bill ought to be that of Steve Eidelman. The hundred-dollar bill is the largest denomination available and so is Steve.

In terms of currency, Steve has seen his efforts purchase independence, inclusion, acceptance, respect and progressive programs for millions of Americans with intellectual and developmental disabilities. In keeping with the symbol and power of the hundred-dollar bill, one thing is certain—the disability community has gotten "change" from Steve Eidelman. Exceptional Parent (EP) Magazine is delighted to welcome Steve to the Editorial Advisory Board and we look forward to his guidance in helping us to prepare for the challenges awaiting us for the next 50 years.

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

Great leaders know all about who they lead. They know because they have been there. Great football coaches started out as players learning the fundamentals. Great chefs started out peeling potatoes. Great CEOs started out in the mail room.

It's a formula that works and, in the case of Joe Macbeth, it had to be that way. Joe started out as a fresh, naïve and raw Direct Support Professional (DSP). His experience, insights, fears and efforts laid the groundwork for his commitment to work for and on behalf of the legions of individuals who are dedicated to supporting individuals with complex disabilities. We are delighted to welcome Joe to the Exceptional Parent Magazine Editorial Advisory Board where we look forward to his helping us to identify areas of interest to the thousands of DSPs that are thirsty for information to help them succeed.

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

ABOUT STEVEN M. EIDELMAN, MBA, MSW

"Be a game changer. The world is already full of players."
– Steve Eidelman

Steven Eidelman is the University of Delaware's H. Rodney Sharp Professor of Human Services Policy and Leadership. He holds joint faculty appointments in the School of Urban Affairs and Public Policy and the Department of Human Development and Family Sciences. Mr. Eidelman is the former Executive Director of the Joseph P. Kennedy Jr. Foundation, leading the organization to implement innovative projects, programs and cutting-edge policies. Prior to his appointment with the University of Delaware, Mr. Eidelman was the Executive Director of The Arc of the United States, an advocacy group for people with cognitive disabilities and their families, which has more than 900 state and local chapters and 100,000 members. Mr. Eidelman also served as Deputy Secretary for Pennsylvania's developmental disability service systems in the Department of Public Welfare.

ABOUT JOSEPH M. MACBETH

"I didn't come to play the game. I came to change it."
– Joe Macbeth

Joseph M. Macbeth is the Chief Executive Officer and President of the National Alliance for Direct Support Professionals (NADSP; www.nadsp.org) and has worked in the field of intellectual and developmental disabilities for nearly 40 years, beginning as a Direct Support Professional. Mr. Macbeth is recognized as an international leader in the advocacy and movement to recognize direct support as a profession, and is a highly sought-after speaker on the workforce challenges that affect the disability system. He co-authored the *Report to the President: America's Direct Support Workforce Crisis: Effects on People with Intellectual Disabilities, Families, Communities* and the *U.S. Economy for the President's Committee for People with Intellectual Disabilities* (PCPID, 2017), he was the Issue Editor for *Impact: The Direct Support Workforce*

(cont.)

PHOTOS PROVIDED BY RICK RADER, MD

WHAT'S HAPPENING

CONGRESS LEAVES DISABLED PEOPLE BEHIND IN COVID-19 RELIEF BILL

WRONG PRIORITIES: The delay of this COVID-19 relief package is a direct failure of Congress to prioritize the American people.

Washington, D.C. – After months of delays and months of coordinated advocacy from the disability community, this week Congress passed another coronavirus relief bill which does not address critical needs of disabled people, our families, and our service providers. Our community is hurting. Our community is dying. More than 40% of the nation's coronavirus related deaths have been people with disabilities in congregate settings, and yet the recent COVID-19 relief bill provides no dedicated funding to support people with disabilities living in their homes and prevent further admissions to congregate settings. The bill also did not provide funding to get disabled people out of dangerous congregate settings where the spread of COVID-19 has been so deadly.

While disabled people grieve the loss of our community due to this virus, we are also struggling to access much needed supports and programs. The COVID-19 relief bill also failed to provide funding for personal protective equipment for paid and unpaid direct support workers, who have provided essential services throughout this pandemic.

We applaud the dedicated support that Congress provided to increase broadband access and provide pandemic-related assistance to families for broadband. People with disabilities experience a significant digital divide, and these dollars will help keep people connected during a time of isolation. Congress did authorize some small stimulus payments, but these payments exclude adult dependents, which means that families of people with disabilities and multi-generational families will not receive adequate equitable relief. The bill included funding for health care providers and for mental health services, some of which could be used for people with disabilities, but these provisions do not say anything about ensuring that people with disabilities can transition out of or be diverted from congregate settings, and there is no guarantee that any funds will be used for this purpose. The extended increases for unemployment, rent, and SNAP assistance, as well as the support for transportation entities and the extension of the eviction moratorium until January 31, 2021 are necessary and should not have taken Congress months to agree upon, leaving millions uncertain of where they would live, how they would eat, how they would afford to care for themselves and their families, and how they themselves would get the care they need.

The significant delay of this COVID-19 relief package is a direct failure of our leaders in Congress to prioritize the American people. We are outraged at the way in which our representatives and leaders in Congress have failed to support the health and well-being of people with disabilities, and Americans at large. This pandemic and its far-reaching economic impacts are far from over, and the new Congress must take immediate action in January to secure increased funding of home and community-based services, paid family leave, funding to support local, Tribal, and state governments, financial aid for back-paying rent and avoiding eviction, extensions of increased unemployment assistance, and more. *[From the AAPD website; 12.23.20]*

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and People with Intellectual, Developmental, and Other Disabilities (University of Minnesota, 2018) and produced an award winning Realistic Job Preview titled "Working as a Direct Support Professional: We Get It Done" (NYSACRA 2011). While working in New York, Mr. Macbeth partnered with the State University of New York (SUNY) by assisting more than 500 direct support professionals advance their college education through the "Disability Studies Certificate." He is a guest faculty at the University of Delaware's National Leadership Consortium on Developmental Disabilities (NLCDD) and currently sits on the board of directors for The Learning Community for Person Centered Practices (TLCPCP) and The College of Direct Support's National Advisory Board. In 2019, he was appointed by the Administration for Community Living (ACL) as a member of the National Quality Forum's (NQF) Committee on Person-Centered Planning and has been recognized as a National Honoree, (2020 National Honors) by the National Historic Recognition Project for significant national contributions in the field of intellectual and developmental disabilities in the US between 2000 and 2020. He lives in Albany, NY.

ABOUT THE AMERICAN ASSOCIATION OF PEOPLE WITH DISABILITIES (AAPD):

The American Association of People with Disabilities (AAPD) is a convener, connector, and catalyst for change, increasing the political and economic power of people with disabilities. As a national cross-disability rights organization, AAPD advocates for full civil rights for the over 56 million Americans with disabilities by promoting equal opportunity, economic power, independent living, and political participation. To learn more, visit the AAPD Web site: www.aapd.com.

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WHAT'S HAPPENING

EP MAGAZINE: INDISPENSABLE TO THE DISABILITY COMMUNITY FOR 50 YEARS

First published in 1971, EP Magazine is set to continue its legacy of excellence in reporting, advocating and innovating for people.

Five decades ago, *Exceptional Parent* (EP) *Magazine* was first published by a small, dedicated group of healthcare professionals and educators led by Maxwell J. Schleifer, PhD. Throughout its 50 year history, *EP Magazine* has chronicled the challenges and triumphs experienced by the special needs community, providing unequalled coverage for families and professionals involved in the care and development of people with disabilities and special healthcare needs.

EP Magazine focuses on providing information and support for the special needs community. The magazine has an expanding readership of print and online readers including parents, families, physicians and professionals who are involved in the care of children and adults special health care needs.

EP THEN AND NOW: Since 1971, EP has provided unequalled coverage for families of people with disabilities and has developed long-term strategic alliances with many major professional medical societies and lay organizations.

Over the years, *EP Magazine* has featured an incredible roster of contributors and columnists who are leaders in their various fields of expertise and who bring their invaluable experience to EP's readership with depth, empathy, personality and humor. Endorsed by the The American Academy of Developmental Medicine & Dentistry (AADMD), *EP Magazine* counts several of its past presidents on its Editorial Advisory Board.

- *EP Magazine addresses topics each month that are vital to the health and wellbeing of the disability community, including Healthcare, Financial Planning, Autism Awareness, Education, Diet and Nutrition and many more.*
- *EP Magazine has covered the legislative landscape throughout the decades, including the Individuals with Disabilities Education Act (IDEA), the Americans with Disabilities Act (ADA) and significant court cases such as Olmstead v. L.C., and continues to track all manner of advocacy initiatives for its audience.*
- *Since taking over as Publisher in 2016, Len Harac has broadened the reach of the publication, establishing a renewed print and digital edition of the monthly magazine, an enhanced web presence integrated with social media, and robust partnerships with several Fortune 500 corporations. Editor In Chief Rick Rader, MD is recognized as one of the most influential voices for disability rights and practical compassion in the country today. Dr. Rader was recently appointed to the National Council on Disability.*

EP provides proprietary, need-to-have information that is useful to parents, families and caregivers as well as teachers, physicians and allied health care professionals. In addition, over the past 50 years EP has developed long-term strategic alliances with many major professional medical societies and lay organizations serving the disabled. EP is always seeking to form partnerships with any and all organizations who prize goals of diversity and inclusion in their missions to serve the disabled community.

EP Magazine is an award-winning publishing and communications company whose mission it is to reach an even wider audience of people with special health care needs and those who care for them. Please join us in celebrating 50 years of this exceptional publication. Learn more about EP Magazine and subscribe today at **www.epmagazine.com** •

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE & DENTISTRY

Preparing Dental Students and Practitioners to Provide Care for Individuals with Disabilities

BY H. BARRY WALDMAN, DDS, MPH, PHD, STEVEN P. PERLMAN, DDS, MSCD, DHL (HON), ALLEN WONG, DDS, EDD AND BARBIE VARTANIAN

"While dentists, in serving the public, may exercise reasonable discretion in selecting patients for their practices, dentists shall not refuse to accept patients into their practice or dental services to patients because of the patient's race, creed, color, gender, sexual orientation, gender identity, national origin or ***disability.****"*[1] (emphasis added) ADA Code of Ethics

Advisory Opinion *"As is the case with all patients, when considering the treatment of patients with a physical, intellectual or developmental disability or disabilities… the individual dentist should determine if he or she has the need of another's skills, knowledge, equipment, or expertise, and if so, consultation or referral… hereof is indicated. Decisions regarding the type of dental treatment provided, or referrals made or suggested, should be made on the same basis as they are made with other patients."* 1 ADA Code of Ethics

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY

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

"The American Dental Association revised its code of ethics (in response to efforts by the National Council on Disabilities) to prohibit denial of care to patients with physical, developmental or intellectual disabilities. In cases where a dentist does not have the equipment or expertise to meet a particular person's disabilities, the code now requires them to refer the patients to an appropriate dentist rather than simply turning them away." [2]

BACKGROUND

It was not until 2004, that the U.S. Commission on Dental Accreditation (CODA) adopted a new standard (with implementation in 2006) stating that "Graduates **must** (sic) be competent in assessing the treatment needs of patients with special needs." [3]

However, the standard (as adopted) did not require hands-on clinical experience during dental school training. Subsequent to the establishment of the new standard, a study of the clinical experience in the care individuals with disabilities indicated that some dental schools had supplemented their curriculum to include clinical experiences in the care of these patients.[4]

In 2019, the ADA Code of Ethics was modified to include *two additional words* referring to the refusal by dentists to treat patients. It now stated: "…dentists shall not refuse to accept patients into their practice or dental services to patients because of the patient's race, creed, color, gender, sexual orientation, gender identity, national origin **or disability.**" [1]

Current dental practitioners: There are barriers in preparing current practitioners to provide care to individuals with disabilities, i.e. the dentists who graduated from dental schools prior to implementation of the CODA programmatic standard. Although an increasing number of state dental licensing boards require dentists to complete a defined number of mandatory continuing education hours as a precondition for relicensure, they do not specify courses for the care of individuals with disabilities. The fact is that a review of state education requirements and education programs in the larger dental conventions provide few, if any courses, for the care of these individuals. For example:

1. The Massachusetts Dental Society "Yankee Institute" listing of license renewal approved continuing education courses in 2019 for dentists, dental hygienists and dental assistants has a listing of programs including: infection control, eating disorders, oral cancer, radiology, ethics, sleep apnea, management, etc. **but none related to the care of people with disabilities.**[5] There was one single listing in 2016 for "Success and preparation for patients with special needs."[6] An e-mail inquiry was sent to the presenter of this continuing education course regarding the makeup of the audience. The following was the response: "On average, I do get a wonderful turnout for my programs (usually over 100 and sometimes close to 200 for the larger meetings) **but in general, the room is full of mostly dental hygienists and dental assistants."** *(emphasis added)* (Personal communication with the presenter)

   One course is listed in 2019 Yankee Dental Congress, "Special Needs Patients" presented by one of us (SPP), while one would get continuing education credit, **it is not mandatory for license renewal.**[7]
2. A review of the 2018 Greater New York Dental Meeting Program and Exhibit Guide provided the following information regarding sessions for the care of individuals with "special needs" or "disabilities":
   - In 2017, there were 52,733 individuals registered for the meeting.
   - In the 200 page program Topic Index Listing, one afternoon session was listed under the section for patients with disabilities offered by a nurse, "Pharmacologic Management of the Geriatric Patient."
   - A second presentation not listed in the index, and most difficult to find was offered by one of us (SPP); "How general dentists can improve the oral health of the disabled and

EACH AND EVERY ONE: Many current practitioners do provide needed care for their patients with disabilities. However, the ADA Code of Professional Conduct now includes the statement that *all* practitioners shall not refuse to accept patients, including those with a disability.

those at risk (medically complex and elderly)" was placed under a Public Health Symposium category. Far less than 100 dental assistant, dental hygienists and dentists attended the session.

- The only other use of the word "disability" in the 200-page listings was a notice, telephone and e-mail numbers for those registrants in need of "disability-related accommodations or wheelchair access information." [8]

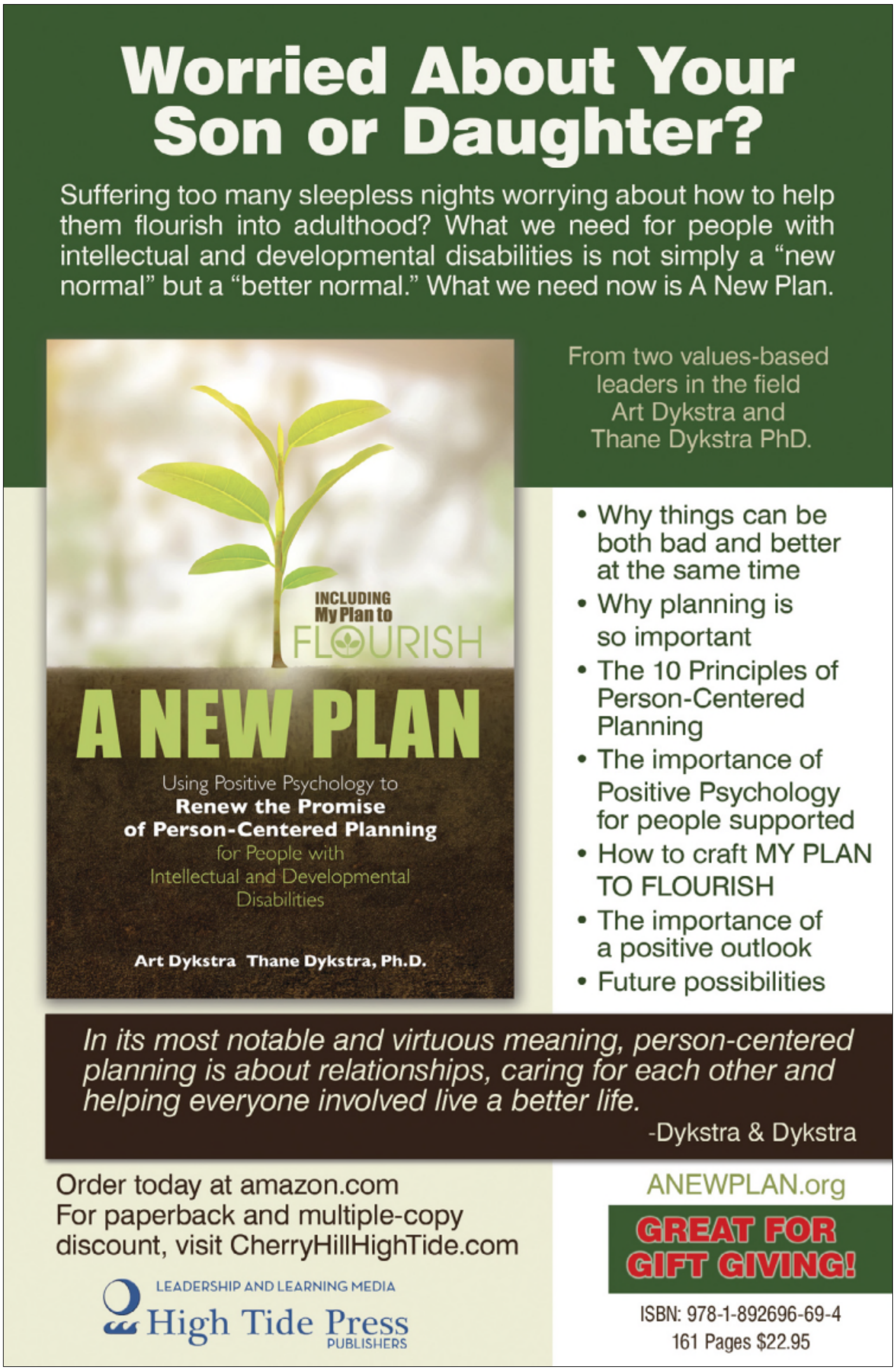
THE REALITY

There are tens of millions of individuals with disabilities who have care needs in our communities. Preparing dental school graduates to provide these services is a critical step that the Commission on Dental Accreditation is considering as it reviews updating the standards (in line with new ethics obligations) to include hands-on clinical experience for the care of these disabilities.

For example, specialty care clinics (such as New York University School of Dentistry and Penn Dental Medicine's Center for People with Disabilities) are: 1) engaging alumni by providing continuing education opportunities for the provision of care to individuals with disabilities, and 2) offering the opportunity for graduates to observe at chairside in an effort to gain a better understanding of the individual patient.

Yes, many current practitioners do provide needed care for their patients with disabilities. However, the ADA Code of Professional Conduct now includes the statement that **ALL** practitioners shall not refuse to accept patients (including those with a) **DISABILITY.**

Surely, the profession and the state licensing authorities will adopt a step in the process to prepare current practitioners to provide the needed services for individuals with disabilities. **If not mandatory requirements at the time of license renewal, how else?** •



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AADMD SALUTES YOU

DSPs - we see you. We see the tireless work you do. We see how much you care for people with ID/ DD – and we thank you. We, **the American Academy of Developmental Medicine & Dentistry and NADSP, our partners in collaborative ID/DD healthcare, appreciate YOU.**

AADMD

ORGANIZATION SPOTLIGHT

Tennessee Disability Pathfinder

BY ELIZABETH TURNER

The Vanderbilt Kennedy Center (VKC) was founded in 1965 as one of 12 original Intellectual and Developmental Disabilities Research Centers (IDDRC). President John F. Kennedy established the IDDRC network to advance the diagnosis, prevention, and treatment of intellectual and developmental disabilities (IDD).

Today, the VKC's programs and activities are broad, including providing support to Vanderbilt University and Vanderbilt University Medical Center researchers who strive to understand typical and atypical development; training tomorrow's educators and disability service providers; developing model service programs and interventions; and disseminating information to impact communities and public policy.

One of the VKC's innovative and highly impactful programs is Tennessee Disability Pathfinder (**https://vkc.vumc.org/vkc/pathfinder**), a statewide disability information and referral service. Pathfinder assists people with disabilities, their families, educators, and other professionals to find and access resources, support, and services within the state. Pathfinder staff work with individuals of all ages, with all types of disabilities, and in all languages spoken, at no charge.

Pathfinder serves within the Community Outreach arm of the VKC's University Center for Excellence in Developmental Disabilities (VKC UCEDD) (**https://vkc.vumc.org/vkc/ucedd**) and is made available to Tennesseans and residents of surrounding states who are willing to travel to receive disability services. It was first established in 1997 as the Tennessee Disability Information and Referral Office, as part of a flagship partnership with the Tennessee Council on Developmental Disabilities (**www.tn.gov/cdd.html**), a state agency that leads initiatives to improve disability policies and practices, educate policymakers and the public about promising practices in the field of disability services, and facilitate collaboration and coordination across public and private organizations.

NO BARRIERS: Pathfinder staff work with individuals of all ages, with all types of disabilities, and in all languages spoken, at no charge.

"Tennessee's disability community told us that it was hard to find information about services, which led us to launch Pathfinder in 1997," said the DD Council's executive director Wanda Willis. "Pathfinder has become a key resource in our state, including to the Latino community through its multicultural program."

Over the years, Pathfinder's services and staff have grown with subsequent partnerships and with additional grant funding agencies within Tennessee, including the Tennessee Departments of Education, Intellectual and Developmental Disabilities, Health, and Human Services/Vocational Rehabilitation.

"Tennessee Disability Pathfinder has been a vital service for so many Tennesseans with disabilities and their families in the years since its inception, and our ability to serve others has only improved with the continued support of so many valued disability advocacy and service partners," said VKC UCEDD co-director Elise McMillan, J.D.

Pathfinder employs a diverse staff that includes professionals, family members, and/or individuals with disabilities with many years of experience working in the disability field. Pathfinder is currently led by program director Megan Hart, M.Ed. McMillan serves as Pathfinder's faculty director.

INFORMATION AND REFERRAL SERVICES ACROSS THE LIFESPAN

Perhaps the most utilized of Tennessee Disability Pathfinder's services is its expansive clearinghouse of disability organizations and disability-related services across the state of Tennessee, both within and outside of Vanderbilt's network. Through a helpline and online resources directory, Pathfinder connects individuals to appropriate community resources, as close to home as possible.

Pathfinder staff typically assist approximately 2,000 individuals per year who reside in nearly 95 Tennessee counties. Some of the most requested needs usually include financial assistance, Family Support Program, interpretation and translation assistance, health care services, and housing information. Resources for children ages 1-12 have been the most sought-after, and autism spectrum disorders are the disability group most represented by individuals seeking assistance.

"Most often, Pathfinder is not the first point of contact for individuals that call or email us, so our staff's personal and professional experience plays an important role in providing one-on-one assistance for each person to be successful in determining and access-

PHOTOS PROVIDED BY MEGAN HART, M.ED

SIGNING ON: Pathfinder staff conduct a Zoom meeting during the Covid-19 crisis. The staff typically assist approximately 2,000 individuals per year who reside in nearly 95 Tennessee counties.

ing the most appropriate resources to meet his or her needs," said Hart.

Those looking for information have the option to speak with a Tennessee Disability Pathfinder staff member over the phone at 1-800-640-4636. The toll-free number is monitored by Pathfinder information and referral coordinators Karen Mevis and Linda Brown, both longtime disability advocates and parents of adult children with disabilities who are eager to help meet the needs of families much like their own.

Those who would prefer to search for information on their own may also access the resources library at their convenience. The resource library (https://vkc.vumc.org/vkc/pathfinder/library), maintained by Pathfinder's database and website coordinator Carvis Russell, includes valuable information sorted by theme. For a more comprehensive search, individuals can search the resource directory (https://vkc.vumc.org/pathsearch) by keyword, county, or region. The Pathfinder website also houses an updated community calendar (https://vkc.vumc.org/pathcal2) with disability-related events across the state. Events often include disability organization support group meetings, workshops, recreational activities, fundraisers, and more.

Pathfinder works closely with other VKC UCEDD programs, including Transition Tennessee (https://transitiontn.org), Tennessee's online home for training and resources on preparing students with disabilities for life after high school. Certain services and supports available to Tennessee children and adolescents with disabilities expire once the adolescent graduates high school, or ages out of the programs, whichever comes first. Pathfinder works alongside Transition Tennessee to provide parents and self-advocates with helpful information on additional forms of support available to adults with disabilities.

"Pathfinder helps students and families navigate their transition to adulthood successfully," said Transition Tennessee educational consultant Rachael Jenkins. "Transition Tennessee includes Pathfinder in the Supports and Partnerships section (https://transitiontn.org/supports-partnerships) of their website, highlighting how Pathfinder can be a resource during the transition process. Pathfinder has even presented at Transition Tennessee's annual conference, and participated in their virtual transition fairs for parents."

TRAINING OPPORTUNITIES, IN PERSON AND ONLINE

In addition to providing service information to Tennessee families, Tennessee Disability Pathfinder also offers regular education and training opportunities.

In a typical year, Pathfinder staff members travel the state to provide free in-person workshops covering topics that are important to families of children with disabilities, such as financial assistance resources and disability supports. These workshops often are co-sponsored alongside regional community organizations and welcome other local groups who may be able to provide additional assistance to families in their county after Pathfinder staff return to Nashville.

Despite the COVID-19 pandemic, Pathfinder has been able to continue their trainings and workshops by going virtual, thereby expanding the number of people served by recording their workshops over Zoom and allowing families to re-visit archived webinars on their Trainings page (https://vkc.vumc.org/vkc/pathfinder/trainings).

Also linked on the Trainings page is a broader VKC UCEDD Online Learning platform (https://ucedd.vkclearning.org) (creation of a free profile required), with archived Pathfinder webinars, as well as online courses on IDD Toolkit training for health-care professionals and advocating for your child's special education needs.

ABOUT TENNESSEE DISABILITY PATHFINDER

YOUR NAVIGATOR ON THE PATH TO COMMUNITY SERVICES

TENNESSEE DISABILITY PATHFINDER

Tennessee Disability Pathfinder, a statewide multilingual information and referral service for disability resources operated by Vanderbilt Kennedy Center, is one of the most important projects of the Council. This central source for disability information was created in 1997 by the Council in response to demand from families all across Tennessee who needed a way to get information about disability services. Today the Departments of Health, Intellectual & Developmental Disabilities, Education, and Human Services/Rehabilitation Services share in the funding of Pathfinder through specialized contracts, while the Council is the primary funder. Information is available via a phone and email helpline, as well as an online searchable database containing over 3,000 agencies. Learn more at https://vkc.vumc.org/vkc/pathfinder/aboutus or sign up for their e-newsletter at https://vkc.vumc.org/vkc/pathfinder/enews.

ACROSS THE LIFESPAN : PARENT TIPS AND RESOURCES

Tennessee Disability Pathfinder staff members Megan Hart, Karen Mevis, and Linda Brown compiled the following list of parent tips and resources, categorized by age group, when it comes to seeking assistance for an individual with a disability:

EARLY INTERVENTION & YOUNG CHILDREN

- If your child was not referred to the Early Intervention Program **(www.benefits.gov/benefit/636)** at the time he/she was diagnosed with a disability, it's important to contact the agency in your state that oversees the program that assists families in getting appropriate information and pediatric therapies from birth until the child is age three. At that point, the child is referred to their home county's school system, and they could be eligible to attend preschool free.
- Parents need to begin to understand that their role as primary advocate for their child with a disability is paramount to that child's life.
- Seek out family-network organizations and learning opportunities for becoming an advocate for your child, such as The Arc **(https://thearc.org)** state and local chapters, Partners in Policymaking program, Family Voices **(https://familyvoices.org)**, and disability-specific organizations such as a local chapter of the Autism Society **(www.autism-society.org/about-the-autism-society/affiliate-network)**, Down Syndrome Association, United Cerebral Palsy (UCP) **(https://ucp.org)**, etc.

SCHOOL AGE

- Connect with a Parent Training and Information Center **(www.parentcenterhub.org/find-your-center)** to learn aboutspecial education rules and procedures, especially areas which will pertain to your child's needs.
- Find an experienced, trained advocate to join you at school team meetings, when your child's Individual Education Plan (IEP) is being created, modified, or updated.
- Talk with your child and others about their loves, abilities, and successes. Expect their success and help their teachers see them as successful, so your child will see a place for themselves in the workforce and in the community.

TRANSITION AGE

- It is never too early to start learning about Future Planning **(https://futureplanning.thearc.org)** topics such as ABLE savings accounts **(https://www.able-now.com)**, Special Needs Trusts, and Supported Decision-Making **(www.supporteddecisionmaking.org)**.
- If you or your child is considering further education opportunities, look into inclusive higher education programs, Disability Services offices at colleges and universities, and potential scholarships or financial aid.

- When researching employment opportunities, consider potential resources such as your state's Vocational Rehabilitation services, American Job Centers, and Ticket-to-Work, just to name a few.
- To continue instilling self-advocacy and independent living skills in your child, consider connecting them with a Center for Independent Living **(https://acl.gov/programs/centers-independent-living/list-cils-and-spils)** for peer support and recreational activities for social and peer engagement. Examples include Easter Seals **(www.easterseals.com)**, Special Olympics **(www.specialolympics.org)**, and/or Next Chapter Book Club **(www.nextchapterbookclub.org)**.
- Narrow the focus with your child and take a deep dive into the program(s) and the path your child may choose. Ask the hard questions like, how long is the wait list?

ADULTHOOD

- Update the future plan together with new information and new goals.
- Look into housing options, long-term support services, and other resources your child may need to live a meaningful life.
- Get organized: are your finances, paperwork, and will in order? If you have not already, it is important to get things in order so that an inheritance from you or a well-meaning relative doesn't cause a person who is dependent on Supplemental Security Income (SSI) **(www.ssa.gov/ssi)** and Medicaid **(www.medicaid.gov)** to lose those government programs? Assets greater than $2,000 can cause that to happen.

AGING

- Take time to ask yourself and your loved one some tough questions: What is important to the person with a disability? How is that communicated to others? Is your loved one with a disability at higher risk for certain medical issues or disease that prompt the need for additional conversations, actions, or planning? When it is needed, who will be the back-up person when the parent/caregiver passes away or becomes incapacitated?
- Connect with an Aging & Disability Resource Center **(https://acl.gov/programs/aging-and-disability-networks/aging-and-disability-resource-centers)** for assistance in connecting with potential services and information about Medicare through SHIP **(www.shiptacenter.org)**.

OTHER LIFESPAN RESOURCES

- State Council on Developmental Disabilities **(https://acl.gov/programs/aging-and-disability-networks/state-councils-developmental-disabilities)**: The 56 Councils across the U.S. and its territories work to address identified needs by conducting advocacy, systems change, and capacity-building efforts that promote self-determination, integration, and inclusion. Key activities include conducting outreach, providing training and technical assistance, removing barriers, developing coalitions, encouraging citizen participation, and keeping policymakers informed about disability issues.
- Protection & Advocacy System **(https://acl.gov/programs/aging-and-disability-networks/state-protection-advocacy-systems)**: Dedicated to the ongoing fight for the personal and civil rights of individuals with disabilities by helping them navigate the legal system to achieve resolution and encourage systems change and to ensure that they are able to exercise their rights to make choices, contribute to society, and live independently.

- University Center for Excellence in Developmental Disabilities **(www.aucd.org/template/page.cfm?id=667)**: Centers work with people with disabilities, members of their families, state and local government agencies, and community providers in projects that provide training, technical assistance, service, research, and information-sharing, with a focus on building the capacity of communities to sustain all their residents.

MULTICULTURAL OUTREACH FOR SPANISH-SPEAKING FAMILIES

Tennessee Disability Pathfinder is proud to serve members of the state's growingly diverse communities through its Multicultural Outreach Program (**https://vkc.vumc.org/vkc/pathfinder/multicultural**). The Program's mission is to help those from culturally and linguistically diverse backgrounds access disability resources and information. To address the needs of Tennessee's growing multicultural population, staff members provide cultural awareness, education, training, and one-on-one help to non-English-speaking Tennesseans. Regardless of nationality or language spoken, free assistance for individuals with disabilities and their families is just a phone call away at (800) 640-4636 or (615) 875-9850.

A vast majority of the multicultural services requested come from members of Tennessee's Spanish-speaking population, so Pathfinder offers Camino Seguro, a statewide online database dedicated to disability resources offered to the Hispanic community with bilingual service providers.

COVID-19 has disproportionately affected Tennessee's Hispanic population, so Camino Seguro has been a valuable asset for the community. In fact, Nashville Mayor John Cooper's Metro Nashville COVID-19 Task Force enlisted the help of statewide Multicultural Outreach coordinator Angelica Deaton to provide information to Spanish-speaking Nashvillians during his regular coronavirus briefings earlier in the year. Since then, Camino Seguro has welcomed another bilingual Multicultural Outreach coordinator, Martha Lopez, to the team.

HERE TO HELP: Program Director Megan Hart is part of a diverse staff with many years of experience working in the disability field.

Pathfinder and its Multicultural Outreach staff have worked closely with the Vanderbilt Kennedy Center's Treatment and Research Institute for Autism Spectrum Disorders (VKC TRIAD) (**https://triad.vumc.org**) to provide translation assistance for its Families First workshops for parents of young children with an autism diagnosis. Deaton and Lopez have been instrumental in providing Spanish translations of autism supports (**https://vkc.vumc.org/vkc/resources/autism**), including manuals and tip sheets for families seeking assistance for their child with autism, from early childhood onto transition age and early adulthood.

"TRIAD provides services and resources across Tennessee, but without the Pathfinder expertise and community integration, we would find it much more difficult to effectively serve and support the individuals and families who are non-English speaking, and who rely on us," said VKC TRIAD director A. Pablo Juarez, M.Ed., BCBA.

PATHFINDER IN THE FACE OF COVID-19

The novel coronavirus hit the state of Tennessee hard in early March 2020, closing schools and businesses indefinitely, while the city of Nashville moved into a "Safer at Home" public health order. For Middle Tennessee, COVID-19 came like a one-two punch after a deadly EF4-scale tornado ripped through parts of East Nashville and residential neighborhoods in the cities of Mt. Juliet, Lebanon, and Cookeville in the early morning hours of Mar. 3.

In the midst of the chaos, Tennessee Disability Pathfinder worked quickly with fellow Vanderbilt Kennedy Center staff members to create a dedicated COVID-19 and Disaster Relief Resources page (**https://vkc.vumc.org/vkc/pathfinder/corona**), providing Tennesseans with contact information for disaster relief organizations as well as links to important resources such as the Centers of Disease Control. The page also features plenty of sharable videos, tip sheets, and print materials for individuals with disabilities, many of which were created by the Vanderbilt Kennedy Center and the Monroe Carrell, Jr., Children's Hospital at Vanderbilt, including visual supports on proper handwashing (**https://vkc.vumc.org/assets/files/resources/visual-supports-handwashing.pdf**) and social stories about social distancing (**https://vkc.vumc.org/assets/files/resources/Social%20Distancing%20Social%20Story.pdf**), intubation (**https://iddtoolkit.vkcsites.org/wp-content/uploads/intubation-prep-tag.pdf**), and wearing a mask (**https://vkc.vumc.org/assets/files/triad/Wearing_a_Mask_During_COVID-19_adj.pdf**).

In the months following, Pathfinder has continued to add additional information as needed from city and state disability organizations covering timely topics such as knowing your rights to healthcare under the law, at-home learning resources, and Tennessee unemployment insurance information.

Tennessee Disability Pathfinder has become such a vital information tool in the fight against COVID-19, it was recently awarded a special grant (beginning January 2021) from Commission on Aging and Disability to continue providing support and creating additional coronavirus resources for aging and disabled populations.

SOCIAL MEDIA AND IN YOUR INBOX

For those who like to keep up with up-to-the-minute information, Tennessee Disability Pathfinder has an active presence on social media, including Facebook and Twitter. Facebook users can access, like, and follow Tennessee Disability Pathfinder (**@TennesseeDisabilityPathfinder**) for regular updates on upcoming Pathfinder trainings, news from disability partners, and links to new products and resources. Likewise, Pathfinder may also be found on Twitter at **@tnpathfinder**.

For Spanish-speaking families, Pathfinder also offers Camino Seguro (**@caminoseguroTN**), with frequent Pathfinder-related posts written in Spanish. The page is maintained by Pathfinder's Multicultural Outreach coordinators. Pathfinder also produces a monthly e-newsletter, The Compass. Each month features articles produced by Pathfinder staff on a new topic. Click **https://familypathfinder.us3.list-manage.com/subscribe?u=7ec625dc46decdfb71336acd4&id=cdad56036a** to subscribe to The Compass. Archived editions of The Compass may be found by clicking **https://us3.campaign-archive.com/home/?u=7ec625dc46decdfb71336acd4&id=cdad56036a**.

For more information about Tennessee Disability Pathfinder, visit the Pathfinder website at **https://vkc.vumc.org/vkc/pathfinder**, or contact program director Megan Hart at **megan.hart@vumc.org** •

ABOUT THE AUTHOR:

Elizabeth Turner is the associate director of Communications and Dissemination for the Vanderbilt Kennedy Center (VKC). In addition to being a content creator, she also serves as lecture and special event coordinator and social media administrator for the VKC's Facebook and Twitter accounts. She's proudly been a part of the VKC staff for eight years, before which she was a journalist and section editor for a newspaper in the Upper Cumberland region of Middle Tennessee. She may be reached at elizabeth.turner@vumc.org.

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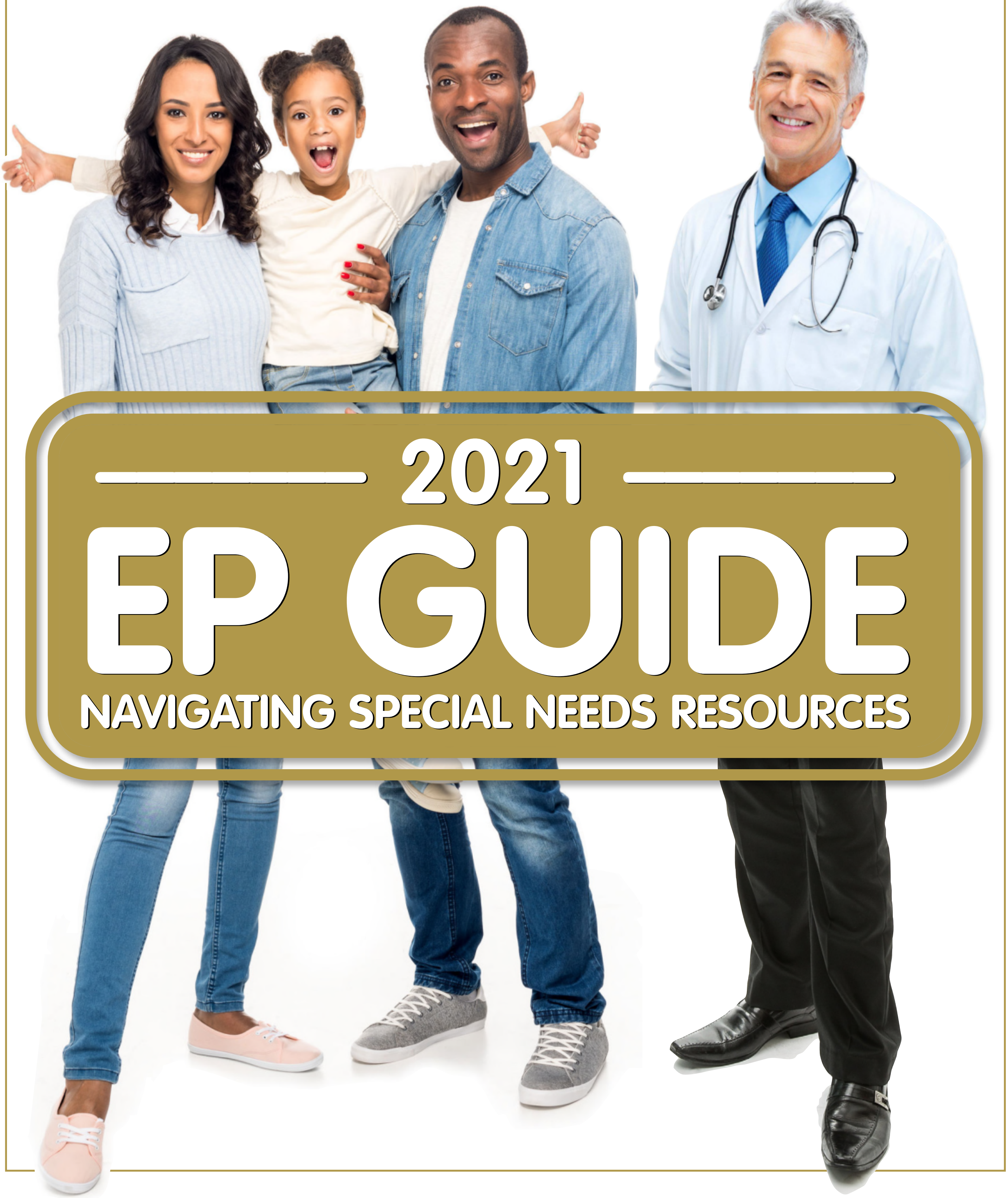

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WHAT AUTISM ORGANIZATIONS CAN I TRUST TO GIVE ME GOOD RECOMMENDATIONS OR RESOURCES?

BY MICHAEL JOHN CARLEY

Disclaimer: *As a conflict-minded Board member of NEXT for Autism,*[1] *the non-profit behind HBO's* Night of Too Many Stars, *I'm not including them in the list of recommended organizations. But my involvement with them hopefully communicates at least something of an approval.*

If you're a newly-diagnosed person with autism, or the loved one of a newly-diagnosed autistic person, you would think that googling "best autism organizations" is a good way to start your search for resources, services, and – if you're less panicked – meaning (i.e. "What does this diagnosis mean to my life?").

Sigh…

The results of such a search will arrive at a myriad of short, well-copyedited pieces, most of which were written in haste – cheerful, peppy haste, but haste nonetheless. The authors of these articles don't tell you the awful histories of the organizations (that for their purposes, they themselves found only on a google search) because they don't take the time to research the organizations and find out. Most national autism organizations that have heinous pasts of euthanasia-like belief systems…they still somehow make it onto those lists. Furthermore, the regrettably still-standing "We swear!... Vaccines cause autism!" organizations also make those lists. Needless to say, it's kind of a crime to be advocating for these organizations, consciously or unconsciously (even if the bigger crime is that these organizations still exist). So, don't trust the internet too much.

The fact also is that if you are new to the world of autism, you will unfortunately have to wade through much more misinformation than you would with other conditions. Celebrity endorsement? Doesn't matter. They sponsored a bill? Doesn't matter.

Why is this? Why can't you get straight answers about autism like you would if you googled about a different condition?

I've written about the long answer numerous times,[2,3,4] but the short answer—by way of explanation and not justification—is that the autism spectrum is simply more diverse than maybe any other non-apparent disability. It's a condition that includes folks who can be incredibly happy while still never adopting spoken language, holding down a steady job for long, or having reciprocated romantic or sexual relationships. And yet, the likes of Albert Einstein, Emily Dickinson, Beethoven…etc. may have had the very same diagnosis (with spectrumites like me falling somewhere in the middle). With such a disparity of needs, this unique diagnosis maybe demands that we never really be the "community" people often refer to us as. It's too complicated an idea, in addition to being a fascinating diagnosis.

Ok. Now that we've made the case why this article, and this type of article, is so needed….

SELECTION CRITERIA

Overall, in this article I'm painfully neglecting many orgs that I know well, and that have good people running them; and that as a result of their omission may never again call me a friend, if not hire me as a speaker. Some just aren't getting it done, some are foreign (to include non-U.S. organizations in this list would have been too exhaustive—so many, many organizations abroad, believe it or not, do great work), some are government-funded service organizations (the good ones therein of whom are REAL heroes) and some are niche organizations that one wouldn't go to as a first source for autism info anyway (I think here especially of orgs like GallopNYC,[5] that facilitates therapeutic horse riding for people with disabilities, the Wrightslaw Special Education Report,[6] or the musical theatre-based Miracle Project[7]). With this list, we're sticking with primarily educational, advocacy and membership organizations. The organizations you'd contact to get recommendations for these other entities.

Our qualifying characteristics now determined, "best" orgs were chosen by some un-mathematical, gut instinct, mish-mash combination of the following four criteria:

1. STABILITY: A PROVEN TRACK RECORD

Needless to say that doing great things over a long haul is proof that you're not just great at the design of your organization, you're great in the implementation as well.

2. ACCURATE AND EMOTIONALLY-HEALTHY INFORMATION

As stated earlier, no organizations should ever be considered for a "best of" list if they've ever entered into "cure" talk, vaccine theory, or used the medical model of disability as an alarmist way to attract attention or raise funds. It's not only scientifically inaccurate, it's mean—to everyone. But it's especially cruel to people on the spectrum. Spouting hysterical rhetoric is also such a treason to so mislead people (mostly parents) who look to you for leadership, and who, in addition to answers, also need you to help them find emotional resolution. These are orgs that pour gasoline on the fires of their constituents, not water. They poisonously led the way before the bipartisanship we see now, encouraging their constituents to be and stay angry, and not to find peace, about a condition that wasn't going anywhere (and that I wouldn't trade for the world).

3. OPERATING COSTS VERSUS PROGRAMS

What percentage of your donation goes to the organization's salaries versus. how much goes to the programs they provide that help people? In fairness, this particular value judgment can't be thought of so simply—many orgs help people directly through their salaried employees. But it's still a litmus test that helps identify those orgs that pay themselves far more than they give back.

4. SPECTRUM LEADERSHIP

(Here's the criteria that's gonna throw even the best of the orgs)

How many people on the spectrum are in senior leadership positions? No, not just the mailroom. Not just unpaid "Advisory Board " members or interns. Real, qualified administrators that get the same level of pay of (if not better than) their neurotypical peers, and who outperform these peers because their experiences only add further quality to their opinions.

Twenty years ago, most got their first glimpse of an autistic speaker at "Autreat," (spectrum-run-) Autism Network International's annual retreat. Well, then there were neurotypical heroes like (the now defunct or obscured) MAAP and AHANY, who allowed our folks to speak in front of audiences and to influence Board conversations. For the early 2000s, these allies revolutionized the thinking of "inclusion," by acknowledging a long-fought fact that not everyone on the spectrum was non-verbal. Prior, many families of our more-challenged brothers and sisters wanted cultural ownership over the word "autism" to portray it as tragedy-only. They were overwhelmed not because autism (as they thought, and were told) was bad. They were overwhelmed because they weren't getting the services they needed.

Listening to the narratives of people on the spectrum…These then-wonderful 2000s-era measuring instruments of progress, under a 2020 spotlight, are woefully inadequate.

People like me – spectrumfolk who've had educational opportunities – understand the dangers of emotional dysregulation, and who have families of their own who are not "train wrecks" (as I heard one clinician say)… We're not unique any more. We may not be the

THE WINNERS! : A SELECTION OF RELIABLE AND TRUSTWORTHY AUTISM ORGANIZATIONS

With all that, the autism organizations (in no particular order) that I believe you can trust for reliable and healthy information are…

THE AUTISTIC SELF-ADVOCACY NETWORK (ASAN)

https://autisticadvocacy.org

Run by, as well as for, people on the spectrum, ASAN provides accurate and healthy information, and are on top of and respond in a timely fashion to, almost every development occurring in the autism world. I'll admit that they were an often dysregulated, "my way or the highway" handful when I ran GRASP,[8] divisively setting spectrum person against spectrum person as a means to promote themselves. But that was a long time ago. And whereas GRASP has all but disappeared since my departure in 2013, ASAN has matured and grown comfortably into the primary voice for people on the spectrum. Under the leadership of Julia Bascom, they became much more strategic in their partnerships, seem infinitely more disciplined in how they accomplish their work, and have truly accelerated what were always their strengths – their brains, policy analysis, and being dedicated to an all-disability inclusive lens. They also lead for the future in their attention to LGBTQ and intersectional approaches.

THE ASPERGER/AUTISM NETWORK (AANE)

www.aane.org

Formerly the Asperger Association of New England, this Massachusetts-based regional parents organization often felt like a national organization. Why? Well, they just felt like they didn't have the crises that so many regional organizations have to go through. Under the long-time steady hand of Dania Jekel, their conferences were professional and not scattered, their programs didn't close abruptly, local pros wanted to work with them, and they fundraised successfully with strategy – not prayers. There never seemed an administrative crisis at AANE, and I never heard a complaint from members about their leadership.

AUTISM ASPERGERS SPECTRUM COALITION FOR EDUCATION NETWORKING AND DEVELOPMENT (AASCEND)

www.aascend.org

Veering now to a different model of regional organization, AASCEND has been volunteer- and not staff-run for quite some time. When compared to AANE in MA, fledgling local orgs in very conservative states, or any others whose locations dramatically change their needs, the San Francisco-based AACEND caters to a very different community, and does so effectively. Historically, they also had one of the first regional, spectrum-led peer support groups that respectfully said, "Hey, thanks but no thanks" to the support they would have garnered by becoming a GRASP branch (AAGW, the Asperger Association of Greater Washington, was another example of an org that preferred its own autonomy, but that like AASCEND, still collaborated with us in a healthy manner.

"probability" we're going to be yet, but we're moving closer, and farther away from "possibility" every day. Under the neurodiverse lens, and encouraged by Diversity & Inclusion ideas, businesses of ALL kinds, not just autism non-profits, can make the relationship with a spectrum employee work. If they have to change their culture in order to onboard that spectrum senior leader? Well, D&I is about rolling up your sleeves, and not hoping everything falls into place by its own.

Autism orgs especially need to roll up those sleeves. For what does that say about their autism knowledge if they can't create that inclusive culture in their own office? Would it irk certain autism org administrators to share leadership with a spectrum person, to have to welcome behavioral differences that you are culturally conditioned to disparage…to be paid less than a person on the spectrum? Honestly, put your game face on, folks.

My crystal ball tells me this will be a large, ethical measuring stick in 5-10 years for autism organizations. You see it at conferences every day; where in the post-event evaluations attendees report having learned 10x more from the $250 spectrum speaker than they did from the $5,000 keynote with a clinical background. Well, now there are spectrum clinicians, spectrum executives, etc. Not only are they young people benefitting from better inclusion opportunities throughout their educations, but they are also older executives languishing on LinkedIn, finally realizing as late diagnoses, why things weren't working out the way they'd expected.

Because of our behavioral differences, we still retain a high unemployment level (75-85% reported by some). If you're a business or non-profit leader who is reading this, our high unemployment numbers, sadly, are a major opportunity for you. For how can you say you know more about autism than a person who has it?

Hopefully, many of y'all found this helpful. When autism hits our lives there's a desperate feeling for short-term answers. But there's also the need for long-term ethical thinking. That goes not just for parents and individuals, but also (if not especially) the organizations entrusted with our care.•

ABOUT THE AUTHOR:

Michael John Carley is the Founder of GRASP, a school consultant, and the author of *Asperger's From the Inside-Out* (Penguin/Perigee 2008), *Unemployed on the Autism Spectrum* (Jessica Kingsley Publishers 2016), the upcoming *Book of Happy, Positive, and Confident Sex for Adults on the Autism Spectrum... and Beyond!*, and the column, "Autism Without Fear," which for four years ran with the Huffington Post. Currently he is the Consultant for Disability Inclusive Culture at New York University, a writer for many, and on Mondays he sees individual clients. For more information on Michael John, or to subscribe to his free newsletter, visit www.michaeljohncarley.com

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OAR

THE ORGANIZATION FOR AUTISM RESEARCH (OAR)

https://researchautism.org

The only research organization to make this list, OAR easily does so because of their emphasis not only on not painting spectrumfolk as needing to be rescued, but also because almost all of the research they fund helps the living. Most others that focus on autism research look at the medical and genetics aspects. But research on nerve synapses or serotonin levels, while informative, won't help an average working-class family with a child with autism, or an individual on the spectrum, for 25-50 years. Studies on housing, or quality of life...this type of research that OAR engages in, is what helps. Also, OAR and this publication (Exceptional Parent magazine) may be the only autism entities that outside of empty lip service, are truly dedicated to supporting military families who are touched by autism. And finally, OAR has the only scholarship program (the Schwallie Family Scholarship) I know of for students on the spectrum..

AUTISM SOCIETY
Improving the Lives of All Affected by Autism

SELECT LOCAL CHAPTERS OF THE AUTISM SOCIETY OF AMERICA (ASA)

www.autism-society.org/about-the-autism-society/affiliate-network

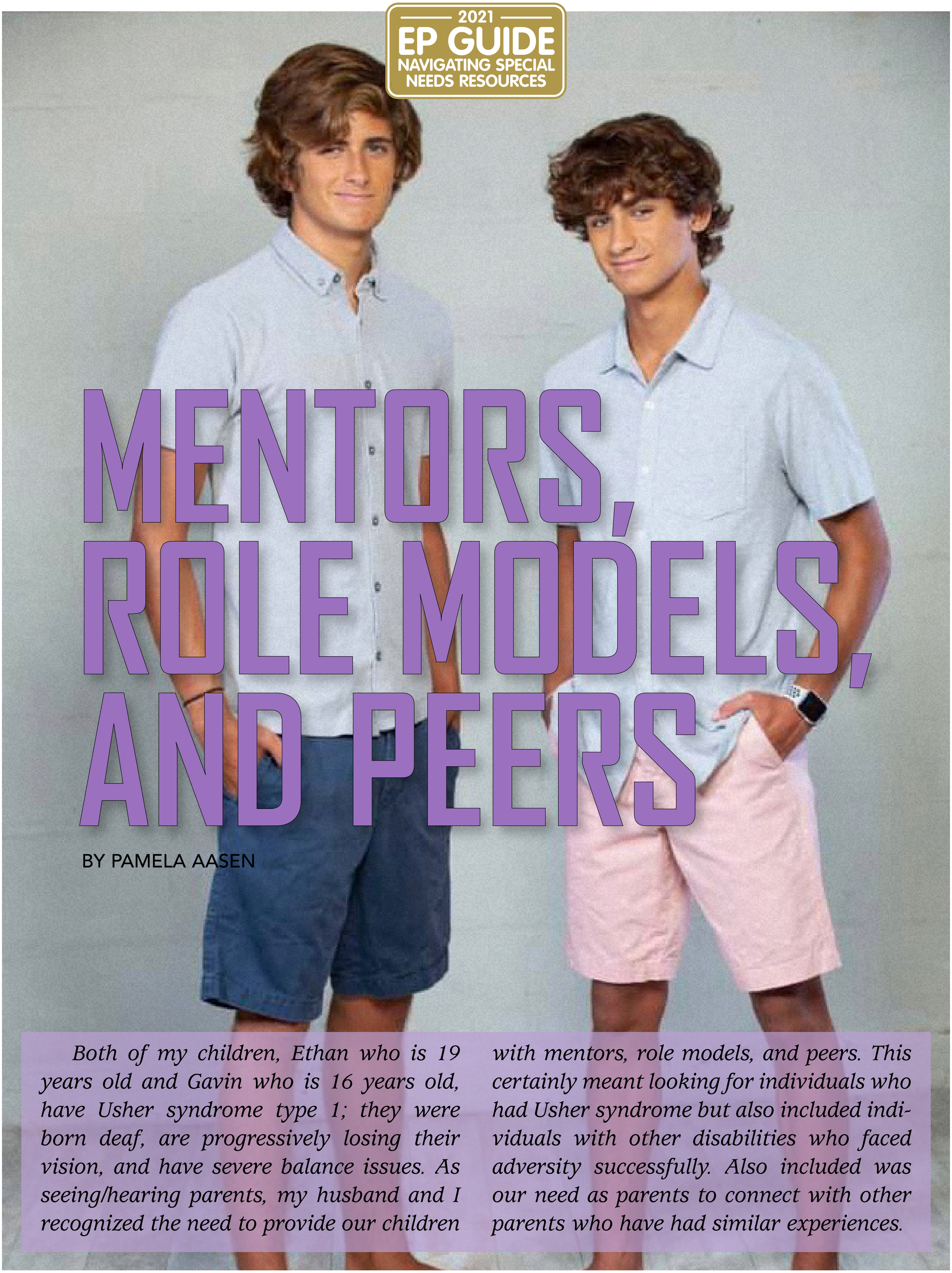
On this list are well-funded orgs, and orgs that are volunteer-run; national orgs and local orgs. In theory, national orgs will never serve their constituents as well as locals because locals know their local needs better. What locals don't know sometimes are solutions. ASA is the ultimate case study. It has roughly 75 chapters, and these can often have polar opposite value systems from one another, and sometimes even different beliefs from the national office. 10-15 years ago, ASA was even in danger of losing dozens of chapters because the local orgs were opposed to the policies and value systems the national org was demanding they implement. What that situation is like now I do not know. But certainly in my time I remember scads that were wonderful sources for their communities (Hudson Valley, Albuquerque...) and plenty that, frankly, either existed only on ASA's website, or were just flat out, comically ineffective.If this were a truly effective article, I'd know which ones to send you to. But the ones I've come across lately are so ineffective. That said, this was an area where I knew some great chapters exist, yet whom I didn't want to omit from this article because I didn't know of them.

Autistic Women & Nonbinary Network (AWN)
Neurodiversity is for Everyone™

AUTISM WOMEN & NONBINARY NETWORK (AWN)

https://awnnetwork.org

Bookending these selections with the two spectrum-run orgs, AWN has grown in every capacity. When Sharon DaVanport founded the org around 2007 or so (Sharon, get a link to your history on the website!), we were just coming into our realization that autism as a "boy's disease" was absolute nonsense. Sharon not only created an org that acted as a safe space for spectrum women, like ASAN she too evolved into an advocate for intersectional and LGBTQ-inclusive practices (no surprise, ASAN and AWN often co-author statements together). AWN also deserves special mention for conducting frequent health care surveys of their members, and then report their findings on their site in many ways – I'm especially impressed by the database resource of spectrum-friendly gynecologists/intimate care providers, and the Trans Autistic Healthcare Guide.



MENTORS, ROLE MODELS, AND PEERS

BY PAMELA AASEN

Both of my children, Ethan who is 19 years old and Gavin who is 16 years old, have Usher syndrome type 1; they were born deaf, are progressively losing their vision, and have severe balance issues. As seeing/hearing parents, my husband and I recognized the need to provide our children with mentors, role models, and peers. This certainly meant looking for individuals who had Usher syndrome but also included individuals with other disabilities who faced adversity successfully. Also included was our need as parents to connect with other parents who have had similar experiences.

PHOTOS PROVIDED BY PAMELA AASEN

Like most parents of a child with a disability, I had no experience to bring to the table. Being the seeing/hearing parents to two deaf blind sons, my husband and I had no understanding of what it was like to be deaf or blind in a hearing and visual world…and definitely not both. There was no history of deafness or blindness in our families; no one to turn to for assistance in understanding what their world might be like. After the initial shock and grief, I knew that it was our first responsibility to make sure they knew they were loved and accepted for who they were. It was our job to advocate for them in an able world and teach them to advocate for themselves. This I understood!

I wrote an article for *Exceptional Parent Magazine* in December 2019 about advocating in the community and the process that developed as my children grew. Visit: **https://reader.mediawiremobile.com/epmagazine/issues/205614/viewer?page=25.**

However, the personal relationships we built were also an important part of that journey and provided the support we needed each step of the way.

PARENT TO PARENT

Neither my husband nor I knew anything about living with a disability. We didn't use the words mentors, role models, and peers; we just knew that our sons needed to know other children and adults with shared experiences. They were quite young then, so our first focus was families. This was the early 2000's and before social media was common, when the world of disabilities was a little more hidden. It was difficult to make connections and easy to feel isolated, but we searched the internet to find organizations that related to our family. We began with attending family events hosted by the Cochlear Implant Program at the Hospital for Sick Children in Toronto. There would be three or four special events a year and the boys would be really excited to see the other children. But given their age, they weren't talking about how they were feeling or what their experiences were, they were just playing together. The awareness of being around other children that had cochlear implants was enough for us at that time. It was really more for me and my husband; we were grateful for the time to talk and compare stories with other parents at different stages in the process of having a child with a cochlear implant. Attending these events also gave us the opportunity to meet families with similarly-aged children.

We eventually met a family with boys the same age as Ethan and Gavin, whose oldest child had a cochlear implant. Our families have been friends for 15 years, a friendship that remains strong even though we have not lived in the same city or country for the past six years. We have also stayed in contact with many of the other families we have met over the years. They were all an integral part of helping us feeling less isolated and provided a support system that was invaluable.

I can't express enough the significance of the parents we have connected with, particularly once Ethan and Gavin were diagnosed with Usher syndrome. As with any parent who has a child with a disability, it is hard for others to understand and relate to the emotions you are going through. Meeting others who have a shared journey is a powerful and vital resource. As difficult as this year has been with restrictions for in-person contact, COVID-19 has brought an unexpected benefit. This year the Usher Syndrome Coalition's annual conference, USH Connections, went virtual and people from many different countries attended. We were able to make connections with families around the world. I believe in this process so much that I became a trained support parent with SPAN's NJ Parent-to-Parent Program and am an USH Ambassador for the Usher Syndrome Coalition to share my story and help connect families and individuals with resources and each other. For the past four years, I have been a facilitator for monthly Family-to-Family Community phone calls developed through a partnership between the National Family Association for Deaf-Blind (NFADB), the National Center on Deaf-Blindness (NCDB), and State Deaf-Blind Projects. These phone calls bring families together in a format that fits with busy lifestyles. I have also been involved with Hands & Voices, a national organization with chapters in many states that offer mentoring and parent support. Finally, I connect with families through Ava's Voice, an organization close to my heart because of my children's involvement, that is dedicated to empowering youth with Usher syndrome and educating communities about Usher syndrome.

SHARED EXPERIENCES: *(Opposite page)* Ethan *(left)* and Gavin; *(Left)* Strong friendships despite the distance; and (above) the author with husband Carlito

PEERS

Though we chose cochlear implants for Ethan and Gavin, which meant intense auditory verbal therapy to teach them listening and spoken language, we wanted to expose them to the Deaf Community. I didn't want them to think I was trying to fix them or pretend they weren't deaf, my husband and I just wanted to give them the opportunity to be a part of the hearing world, too. But the reality is, they are deaf and the Deaf Community is diverse. Along with having peers in the Cochlear Implant community, we wanted them to see other children with deafness or hearing loss who used American Sign Language to communicate. So, they attended an American Sign Language summer camp for a few summers for children who were Deaf or Hard of Hearing and their siblings.

When we learned they had Usher syndrome, a rare syndrome that affects an estimated 400,000 people worldwide, we knew that it would be a challenge to find peers in our community. When we moved to New Jersey in 2014, our research led to an organization, Ava's Voice, that supported a young girl with Usher syndrome. We really didn't appreciate how much that connection would mean at the time but now our families are linked forever. In some ways, Ethan and Gavin are fortunate because, being brothers, they have a support system within our family. They understand what each other is going through. But the bond they have built with Ava is beyond anything they can give each other. The importance of having that peer support is immediately obvious when they get together and the sense of freeness they exude is tangible; nothing can replace being around someone who is experiencing the same challenges and is not judging you. The three of them also face life with the same unapologetic approach and confidence in who they are. Ethan also had the opportunity to experience this in 2018, when he attended the Explore Your Future program for college bound deaf and hard of hearing students at the Rochester Institute of Technology, the college he now attends. I will never forget when he came home and talked about how much he enjoyed the program and said the words that brought tears to my eyes, "It was the first time in my life I felt I didn't have to explain myself."

Ethan and Gavin again experienced this freedom when they attended the first ever, week-long summer camp, USHthis, in 2019 for youth with Usher syndrome, Gavin as a camper and Ethan as a counselor, hosted by Ava's Voice at the Forest Lake Camp in Chestertown, New York. It hit me even more how fortunate Ethan, Gavin and Ava were to have each other, as many of these campers and counselors had never been around someone else with Usher syndrome. At the start of the camp, while most were excited for the opportunity, some were also skeptical and doubted that it would be helpful to share what it was like to be deaf and going blind. By the end of the week, there wasn't one of them who hadn't found it to be a meaningful and profound experience. Certainly just being around others with that familiarity of living with Usher syndrome was meaningful but when they shared, they found out how much they related to each other, regardless of culture, family background, or interests.

ABSOLUTELY crUSHING IT: USHthis Summer Youth Camp is a week long sleep away camp where participants engage with peers, acquire strategies to resolve challenges and foster connections that will last a lifetime.

ROLE MODELS

Certainly, having peers to relate to is important in the life of a child with a disability but they also need to see successful adults who are like them. We set about doing this in different ways…the first happened by accident about six months after we had learned that Ethan and Gavin had Usher syndrome. It was 2010 and Canada was hosting the Winter Olympics. There was a lot in the news about a Canadian Paralympic skier who was blind. It seemed like a good opportunity for the boys to see someone who was visually impaired competing at a national level. As we watched him and other Paralympic athletes, the boys were inspired to pick a Paralympic sport. Given that we were in Canada at the time and skiing regularly, it was no surprise that they chose skiing. I had no idea at the time that one day the boys would be competing at US National Paralympic swim and track & field events.

We always keep our eye out for stories that highlight adults like them having success in different parts of life. They met a young man who has cochlear implants who was a race car driver. They read a story about another young man with a cochlear implant who was playing for a minor league baseball team. They watched two Deaf individuals compete on *Dancing with the Stars*, and a Gap commercial featuring two women with Usher syndrome. Ethan went to a camp to meet blind engineers because he wanted to study engineering in college. They learned about an author, psychologist and extreme athlete who has Usher syndrome, and about the first deaf-blind Harvard graduate and an educator with Usher syndrome. As they began their own venture into Paralympic swimming, they discovered a Paralympic gold medalist swimmer with Usher syndrome. And there is the successful charitable organization Two Blind Brothers. We can also look to organizations who feature successful individuals and tell the stories of regular people who are bravely facing their challenges with determination. We feel fortunate to have the Usher Syndrome Society, which gives a face to Usher syndrome through photojournalism and video storytelling for those who have not heard of the disorder and for those looking for stories about people like them.

The other thing about role models is they don't have to have the same disability. When we watch the Paralympics, we are not just inspired by those with Usher syndrome. Everyone across the world has been inspired by Terry Fox's run across Canada and

PHOTOS COURTESY AVA'S VOICE

Rick Hansen's wheelchair journey around the world. More recently, the individual who was the first person with Down syndrome to complete a marathon did not just inspire those with Down syndrome. The important take away is that our children are looking at people who have succeeded in spite of challenges and barriers.

MENTORS

When Ethan and Gavin were young, along with sending them to an ASL camp, I discovered an organization in Canada, Silent Voice, that had Deaf Mentors who would come into a family's home to teach ASL and introduce the family to the Deaf Community. Many states offer Deaf Mentor programs through family-based organizations or Schools for the Deaf. New Jersey has a Deaf Mentor Program through SPAN, of which I am the Project Director. My goal at that time was to show them different communication choices in the Deaf Community and also expose them to different languages. Their father was Spanish-speaking so they also went to Spanish school for a short time. Though I feel these opportunities were important and appreciated, their lives have been mostly mainstream and in English. For most of their lives, they have been very successful cochlear implant users, but there is no guarantee the implants will work forever. As they have gotten older, they have expressed interest again in learning ASL and, if it is ever necessary, they have had that exposure and it won't be completely foreign to them.

MODEL BEHAVIOR: Becca Meyers, Paralympic swimmer *(above)* and a Gap commercial *(right)* featuring Hannah Corderman & Rebecca Alexander. Ethan and Gavin's family always keep their eyes out for stories that highlight adults like them having success in different parts of life.

My oldest son, Ethan, is currently taking ASL at the Rochester Institute of Technology, which houses the National Technical Institute for the Deaf. They have extraordinary support and mentoring services available for D/HH students in every communication

NOW HEAR THIS : HEARING LOSS AND USHER SYNDROME RESOURCES

SPAN NEW JERSEY DEAF MENTOR PROGRAM
https://spanadvocacy.org/programs/ehdi

DEAF/HARD OF HEARING ADULT INVOLVEMENT PROGRAMS BY STATE
www.infanthearing.org/dhhadultinvolvement/states/index.html

CENTERS FOR DISEASE CONTROL & PREVENTION
Hearing Loss Information for Families
(includes contact for each state)
www.cdc.gov/ncbddd/hearingloss/families.html

NATIONAL MENTORING RESOURCE CENTER
https://nationalmentoringresourcecenter.org

PARENT-TO-PARENT USA
www.p2pusa.org

HANDS & VOICES
www.handsandvoices.org

USHER SYNDROME

AVA'S VOICE
www.avasvoice.org

USHthis SUMMER YOUTH CAMP
https://avasvoice.org/ushthis

USHER SYNDROME SOCIETY
www.ushersyndromesociety.org

USHER SYNDROME COALITION
www.usher-syndrome.org

NATIONAL CENTER ON DEAF-BLINDNESS
https://nationaldb.org

NATIONAL FAMILY ASSOCIATION FOR DEAF BLIND
https://nfadb.org

NEW JERSEY STATEWIDE PARENT TO PARENT
https://spanadvocacy.org/programs/p2p

TWO BLIND BROTHERS
https://twoblindbrothers.com

PHOTOS COURTESY TEAM USA (TOP); USHERSYNDROMESOCIETY.ORG (BOTTOM)

mode. They have over 1000 Deaf, Hard of Hearing and Deaf Blind students and are building a network of successful professionals in an environment where they can fit in and pursue their dreams.

MOMENTS BIG AND SMALL: *(Above)* Celebrating Ethan's high school graduation; *(left)* SPAN Deaf Mentor Program participants conduct an exercise together.

A lot of research has been done on Deaf Mentors and Mentors for children with disabilities. The National Mentoring Resource Center's review of that research found that, "Potential benefits of mentoring programs for youth with disabilities include several in the areas of academic and career development, employment, psychosocial health and quality of life, transition, and life skills." (Lindsay, S and Munson, M. "Mentoring for Youth with Disabilities" National Mentoring Resource Center, October 2018, www.nationalmentoringresourcecenter.org).

FORMING RELATIONSHIPS

The differentiation I make between role models and mentors as I write about them is the personal relationship. When I looked for role models for my children to look up to, we didn't necessarily know them, but I looked for someone I could tell them about, someone they could research, or a story they could read about or watch on TV. Ethan and Gavin were fortunate to have formed relationships with some of these people who have now become their mentors. The bond that has been forged is lifelong and one in which age difference does not matter; it is the relationship of shared experiences and mutual understanding.

I can't change the reality of their disability for my children, I can only support them and try my best to give them what they need to build their confidence, find their inner strength, and develop the fortitude to work hard to succeed and achieve their dreams. It was my hope so many years ago that what I can't provide for them, they could find through mentors, role models, and their peers. That hope is coming true, and now I hope as they find success and achieve their goals, they can in turn be peers, mentors, and role models for others.•

ABOUT THE AUTHOR:

Pamela Aasen is the parent of two children with multiple disabilities, and serves as the Director of the EHDI (Early Hearing Detection & Intervention) Mentoring and Family Engagement Project at SPAN Parent Advocacy Network. For more information, see https://spanadvocacy.org/programs/ehdi

Have you been infected by stigma? Take a 3 question, multiple choice quiz to find out and help spread the cure.

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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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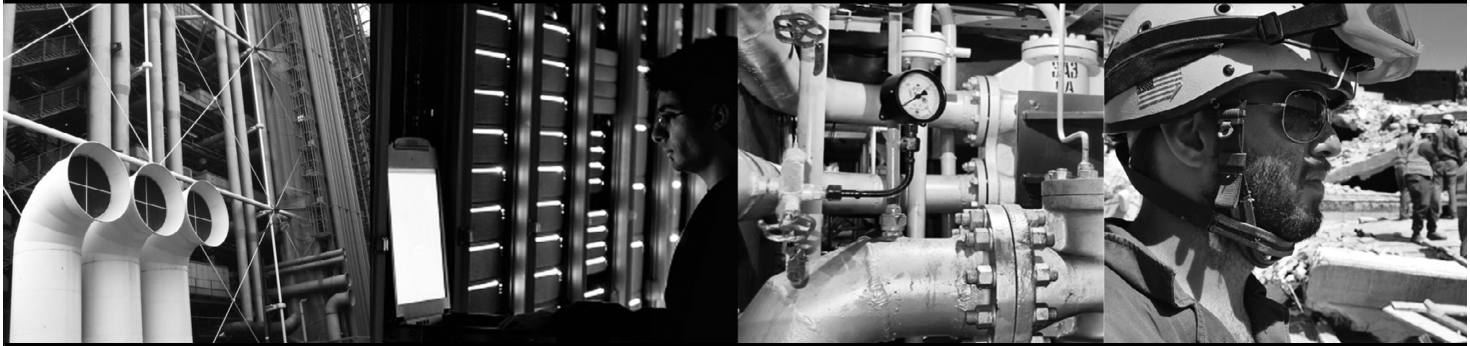

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Building Resilience

RESOURCES TO HELP FAMILIES GROW FROM CHALLENGING TIMES

BY CAROLINE COFFIELD, STEPHANIE MICHAEL AND DEEPA SRINIVASAVARADAN

The ability to cope with stresses and continue to move forward is known as ***resilience*** *(American Psychological Association, 2012*[1]*). While certain factors contribute to some people being more resilient than others, everyone can develop and strengthen their ability to endure, bounce back, and grow from adversity. Being resilient doesn't mean that you won't experience stress or trauma, but that when you do, you have developed some tools that can help you get through hard times.*

STRONGER TOGETHER Using the Strengthening Families approach to building resilience can benefit families of children with disabilities and special health care needs by offering small, but meaningful changes families can incorporate into their lives to enhance strengths.

The COVID-19 pandemic, and the nation's response to it, have created stress for all of us, but particularly for families with children with special health care needs or disabilities. The experience of being home, with many communities shuttered, businesses and services closed, schools moved to virtual learning, and supports provided virtually, if at all, has been extremely challenging. Stress, social isolation, and new ways of accessing school, work, and other services have tested our collective capacity to adapt in the midst of an ever-evolving public health crisis. Now, more than ever, a focus on resilience among families is critical.

One way of building resilience among families is through the *Strengthening Families* approach. This approach was introduced in 2003 by the Center for the Study of Social Policy (CSSP) to help families identify and build on their own strengths in five different categories, called protective factors:[2]

- *Parental resilience*
- *Social connections*
- *Knowledge of parenting and child development*
- *Concrete support in times of need*
- *Social and emotional competence of children*

Using the *Strengthening Families* approach to building resilience can benefit all families, including those of children with disabilities and special health care needs, by offering small, but meaningful changes families can incorporate into their lives to enhance strengths. This article will describe each protective factor in this approach along with related resources for building resilience through crisis and change.

Parental Resilience and Social Connections

No one can prevent stress or crisis from happening in their lives; however, it is possible to find the tools needed to respond effectively so a crisis does not escalate, and to effectively minimize the ways a crisis might negatively impact parenting practices.

In the *Strengthening Families* framework, we think about two different components of resilience – the ability to function well under stress and the ability to parent well in times of stress. Parents and caregivers may exhibit greater resilience in one area than in the other. We need to think about both as we look at strategies parents can use to strengthen resilience.

Networks of support are essential to parents. Friends, family members, neighbors and community members often provide emotional support, help solve problems, offer parenting advice, and give concrete assistance. Social connections also offer opportunities for people to "give back," an important part of bolstering self-esteem, as well as a benefit for the community.

WHAT TO EXPECT : PROMOTING DEVELOPMENTAL MONITORING AND SCREENING AMONG PARENTS

There are a growing number of resources designed to help promote developmental monitoring and screening among parents, especially among parents of very young children, including:

Learn the Signs. Act Early.
Ambassadors

CDC'S "LEARN THE SIGNS. ACT EARLY."

www.cdc.gov/ncbddd/actearly/parents/index.html

This program led by the Centers for Disease Control and Prevention that aims to improve early identification of children with autism and other developmental disabilities so children and families can get the services and support they need as early as possible. The program encourages parents and providers to learn the signs of healthy development, monitor every child's early development, and take action when there is a concern. The program offers free, parent-friendly checklists and other tools to make developmental monitoring practical and easy.

Division for Early Childhood
of the Council for Exceptional Children

DIVISION FOR EARLY CHILDHOOD RECOMMENDED PRACTICES (DEC RPS)

www.dec-sped.org/dec-recommended-practices

The DEC RPs provide guidance to practitioners and families about ways to improve learning outcomes and promote the development of children (0-5) who have or are at-risk for developmental delays or disabilities. The DEC RPs help bridge the gap between research and practice by highlighting practices that have been shown to result in better outcomes for children, their families, and the personnel who serve them. The RPs consists of eight domains:

- Assessment
- Environment
- Family
- Instruction
- Interaction
- Leadership
- Teaming
- Transition

ecta
Early Childhood
Technical Assistance Center

EARLY CHILDHOOD TECHNICAL ASSISTANCE (ECTA) CENTER

http://ectacenter.org/decrp

The Early Childhood Technical Assistance (ECTA) Center has developed a suite of resources available, free of charge, to support practitioners, families, and professional development providers in the use of the DEC RPs. Key TA products available include:

- Performance Checklists for practitioners
- Practice Guides for practitioners
- Practice Guides for families **https://ectacenter.org/decrp/type-pgfamily.asp**
- Guidelines for Selecting Checklists and Practice Guides
- Resources for Professional Development Providers

Parents of children with disabilities report less stress and lower feelings of depression when they have access to social support (Dunn et al., 2001[3]). While many parents of children with disabilities credit their children for strengthened family ties and expanded social networks, some families may experience loss of friendships or feelings of isolation (Paster, Brandwein, & Walsh, 2009[4]). Isolated families may need extra help in reaching out to build positive relationships.

The Mapping Relationships tool, developed by the Charting the LifeCourse Nexus, can help you identify the different people in your life and the ways they support you and your family. It can also be used to guide conversations about the future and who may fill those roles when others are no longer able. To access the Mapping Relationships tool, visit **www.lifecoursetools.com/lifecourse-library/foundational-tools/family-perspective/**

Knowledge of Parenting and Child Development

Parents who have accurate information about child development and appropriate expectations for their child's behavior are able to see their children in a positive light. As a parent, you know your child best. Knowing what to expect from your child at a particular age can help relieve stress. It can also point toward clear action when these expectations and developmental milestones are not met. Information about child development can come from many sources, including family members, friends, physicians, parent education classes, and the plethora of parenting resources available online. Regardless of the source, information is likely to be most helpful and effective if it comes at the time parents need it to understand their own children.

Children with special health care needs should also be monitored and screened for developmental delays and, depending on their condition, they may need more frequent monitoring and screening *(See resource box, below)*.

Concrete Support in Times of Need

Oftentimes, we take our everyday successes for granted and focus on how far we have to go, forgetting to consider how far we have come. Think about the things you have accomplished, large and small, and the barriers that you have overcome. Now think about the people, institutions, and organizations that helped you achieve those accomplishments: a partner; a family member; a hospital; a non-profit organization. Could you have done it on your own? Maybe, but how much easier was it with their help? That's what the concept of Concrete Support in Times of Need is all about - acknowledging when support is needed and being able to access that support for the growth and healthy development of you and your family. When support is easily accessible, it can reduce familial stress, and we all want that, especially during a pandemic.

An important element of this protective factor is being resourceful. This means that we are able to find creative ways to solve problems, are persistent, and work with what we have and know in order to make

ZERO TO THREE
Early connections last a lifetime

ZERO TO THREE

www.zerotothree.org

Zero to Three is a non-profit organization that works to ensure that babies and toddlers benefit from the early connections critical to their well-being and development. It has a variety of resources on accomplishing this during the early years.

Parenting and Family Relationships
Division of Extension

UNIVERSITY OF WISCONSIN-MADISON RESOURCES ON TEENAGERS AND ADOLESCENT DEVELOPMENT

https://parenting.extension.wisc.edu/teenagers/additional-resources-on-teenagers

ParentTeenConnect

www.parenteenconnect.org/learn-more

Having resources related to child development can be useful as children continue to age. Some of the parenting questions or challenges experienced by families of adolescents with special health care needs and disabilities will be unique, but others will be similar to the concerns experienced by other families of children the same age. Knowing where to go for accurate information in each of these scenarios is critical.

GENERAL PARENTING RESOURCES

CDC

Essentials for Parenting

www.cdc.gov/parents/essentials/index.html

Child Development

www.cdc.gov/ncbddd/childdevelopment/index.html

AMERICAN PSYCHOLOGICAL ASSOCIATION (APA)

www.apa.org/monitor/2018/04/parenting-resources

VERYWELL FAMILY

www.verywellfamily.com/parenting-4157353

PARENT CENTER HUB

www.parentcenterhub.org/journey

things happen. Inc.com (www.inc.com/bill-murphy-jr/7-things-really-resourceful-people-do.html) notes these among the seven things that resourceful people do:

1. ***Bend the rules:*** *Rules have a purpose, but when they block progress, a truly resourceful person chooses progress. They decide to get things done, not just go along with how things have always been done.*
2. ***Look for the common good:*** *Resourceful people recognize that they need help. Finding out how to show people that by helping you, they can help themselves, too, sets you up to be more likely to find success.*
3. ***Adapt and apply other experiences:*** *There may not always be a clear path to your goal, but think about how you or others got things done and used challenges as advantages.*
4. ***Play a few hands at once:*** *A plan might not work out, so really resourceful people are always working on multiple plans.*
5. ***Dare to ask for what you need:*** *Your original plan may not have succeeded, however, the experience and the contacts made in the process may lead to other opportunities you never even considered!*

This protective factor is also about understanding your rights to receive available services and being able to navigate through service systems. Many such services and service systems are organized at the state and local level. Therefore, the best way to better understand these rights is to connect with local community resources such as advocacy/family organizations in your state who are in the best position to help you understand the services and systems available in your community. *(See resource box, below).*

Social and Emotional Competence of Children

Social and emotional competence is a child's ability to interact in a positive way with others, communicate feelings positively, and regulate behavior. Skills needed for healthy social and emotional development can include: self- esteem, self-confidence, friend-making skills, self-control, persistence, problem solving, self-sufficiency, focus, patience, good communication skills, empathy, and knowing right from wrong. All of these skills play a critical role in a child's overall wellbeing. Although this protective factor is focused on children, parents and caregivers are really at the heart of it. It is based on the idea that family and child interactions help children develop critical relationship skills like communicating clearly and recognizing and regulating their emotions. Explore resources from The Center on the Social and Emotional Foundations of Early Learning to assist with teaching social emotional health skills: http://csefel.vanderbilt.edu/resources/family.html

To engage in healthy interactions with their children, parents and caregivers must first engage in healthy self-interactions. Proper self-care, or doing things that make you happy and feel good about yourself, can help in achieving this protective factor by improving your mood. When you are in a good mood, it is easier to respond warmly and consistently to your child's needs, which contributes to feelings of satisfaction about your parental role. All too often, parents and caregivers ignore their own needs for the sake of taking care of their child, especially if their needs seem more present and pressing. Self-care is not an indulgence. It is the ongoing practice of keeping ourselves physically and emotionally healthy.

IN YOUR COMMUNITY : PARENT WORKSHOPS, SUPPORT GROUPS, RECREATIONAL PROGRAMS & OTHER RESOURCES

These local organizations may also provide support for you to navigate systems of care to access information about parent workshops, support groups, recreational programs, etc.

PARENT TRAINING AND INFORMATION CENTERS

www.parentcenterhub.org/find-yourcenter

for example, are funded by the US Department of Education to offer information, training, individual assistance, and emotional support to families of children with a disability, special health care need, or mental health concern, and assist with finding information, resources, and services. There is at least one Parent Center in every state; larger states have multiple centers organized by geographic area of service.

NFFCMH
National Federation of Families for Children's Mental Health

FEDERATION OF FAMILIES FOR CHILDREN'S MENTAL HEALTH CHAPTERS

www.ffcmh.org/our-affiliates

There are over 100 chapters of the National Federation of Families serving families of children, youth, and young adults with emotional, behavioral, and mental health challenges.

FAMILY VOICES®

FAMILY-TO-FAMILY HEALTH INFORMATION CENTER

https://familyvoices.org

F2FHICS are family-led centers funded by the Health Resources and Services Administration (HRSA). There is one F2F HIC in each state, in the District of Columbia, in five U.S. territories, and there are three F2Fs serving tribal communities. Each F2F is staffed by highly-skilled, knowledgeable family members who have first-hand experience and understanding of the challenges faced by families of children and youth with special healthcare needs (CYSHCN). These uniquely qualified staff provide critical support to families caring for CYSHCN, particularly families of children with complex needs and those from diverse communities. F2Fs also assist providers, state and federal agencies, legislators, and other stakeholders to better understand and serve CYSHCN and their families.

P2P USA
Parent to Parent USA

PARENT TO PARENT USA AFFILIATES

www.p2pusa.org/parents

Parent to Parent programs pair parents of children with disabilities and special healthcare needs to trained Support Parents for support and connection to resources.

The Program for Early Parent Support (PEPS), a nonprofit organization that has helped parents connect and grow as they begin their journey into parenthood (**www.peps.org/ParentResources/by-topic/self-care/self-care-for-parents**), offers great suggestions for parent self-care, including **meeting physical needs like:**

1. *Exercising, on your own and as a family*
2. *Sleeping (as much as you can)*
3. *Eating right: food affects mood, so try to cut down on sugars and processed foods*
4. *Going for a long walk outdoors*

…meeting emotional needs like:

1. *Being creative/flexible about social activities you can work around your child's needs*
2. *Scheduling time each day to talk to another adult*
3. *Allowing yourself to cry*
4. *Finding things that make you laugh*

…meeting intellectual needs like:

1. *Listening to radio programs, audio books, or podcasts from the web while you drive, or while you work around the house.*
2. *If your child is doing an art project, sit down and create your own art!*
3. *Writing – stories, a blog, a personal journal – to get your thoughts out on paper*
4. *Returning to old hobbies you may not have pursued in a long time*

…and meeting spiritual needs like:

1. *Going to religious services*
2. *Meditating or praying each morning, or each evening*
3. *Spending time outdoors*
4. *Contributing to causes you believe in*

Fostering a strong and secure parent-child relationship is also crucial in this factor. Zero to Three (zerotothree.org) has a variety of resources on accomplishing this during the early years. One resource in particular, Tips for Families: Coronavirus (**www.zerotothree.org/resources/3210-tips-for-families-coronavirus**), offers relevant tips for families, including age-appropriate responses to common questions, a guide to self-care, and activities for young children experiencing social distancing.

The Think Babies™ Infant and Early Childhood Mental Health Resource List (**www.zerotothree.org/resources/2195-think-babies-infant-and-early-childhood-mental-health-resource-list**), offers policy briefs, fact sheets, websites and tools to help you learn more about infant and early childhood mental health services.

This protective factor is also about teaching children how to identify and manage their emotions by identifying and managing our own emotions. At a time when social distancing, quarantining, mask-wearing, and frequent hand-washing to avoid COVID-19 are all too familiar, as parents, being in control of our emotions can be a tall order! With this in mind, it is still important to remember that you are your child's first, and most important, teacher. Practicing self-care and knowing when to ask for help, as mentioned above, are critical components in being able to manage your emotions. Zero to Three (**www.zerotothree.org/search?q=managing%20emotions**) also has some great tips on this skill! *See resource box, left).*

Fostering Resilience Amid the COVID-19 Pandemic

The global response to COVID-19 has changed daily life in many ways for many people. Yet, child development has not paused, and supporting children, families, and care providers of all kinds is as important as ever.

Each of the national parent-led, family-serving organizations listed above have specific resources relating to COVID-19.

NEEDED SKILLS : SOCIAL & EMOTIONAL COMPETENCE

SUPPORTING SOCIAL AND EMOTIONAL COMPETENCE IN CHILDREN

US DEPARTMENT OF EDUCATION
www2.ed.gov/about/inits/ed/earlylearning/talk-read-sing/feelings-teachers.pdf

NATIONAL ASSOC. FOR THE EDUCATION OF YOUNG CHILDREN
Supporting social and emotional competence in children
www.naeyc.org/resources/pubs/yc/mar2018/promoting-social-and-emotional-health

SUPPORTING SOCIAL AND EMOTIONAL COMPETENCE OF OLDER CHILDREN

VIRTUAL LAB SCHOOL
www.virtuallabschool.org/school-age/social-emotional/lesson-2

CARNEGIE CORPORATION
www.carnegie.org/topics/topic-articles/student-success/social-emotional-learning-helping-teens-navigate-all-the-things

CARNEGIE CORPORATION
https://nobelcoaching.com/emotional-skills

COPING WITH COVID : PANDEMIC RESOURCES

CDC
CDC's COVID-19 Parental Resource Kit
www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/parental-resource-kit/early-childhood.html

HARVARD CENTER ON THE DEVELOPING CHILD
How to Support Children
https://developingchild.harvard.edu/resources/how-to-support-children-and-yourself-during-the-covid-19-outbreak
How to Help Families and Staff
https://developingchild.harvard.edu/resources/how-to-help-families-and-staff-build-resilience-during-the-covid-19-outbreak

The Early Childhood Technical Assistance Center provides a list of resources related to fostering resilience among children and families during the pandemic. Resources listed here include those specific to returning to childcare settings post-shut down; virtual schooling; and helping children understand and cope with social distancing, masks, and other restrictions. **https://ectacenter.org/topics/disaster/coronavirus-talking.asp**

In Conclusion

Resilience is not only about "bouncing back" after a stressful event. It is also about "bouncing forward." In the face of challenges, resilience allows us to identify our motivations, reprioritize, and shift course so that we can keep going. This past year and the COVID-19 pandemic have challenged us all to continually bounce forward. As we keep navigating these times of stress and uncertainty, we hope that some of the resources provided here are helpful in supporting you and your family. environment under the current circumstances. •

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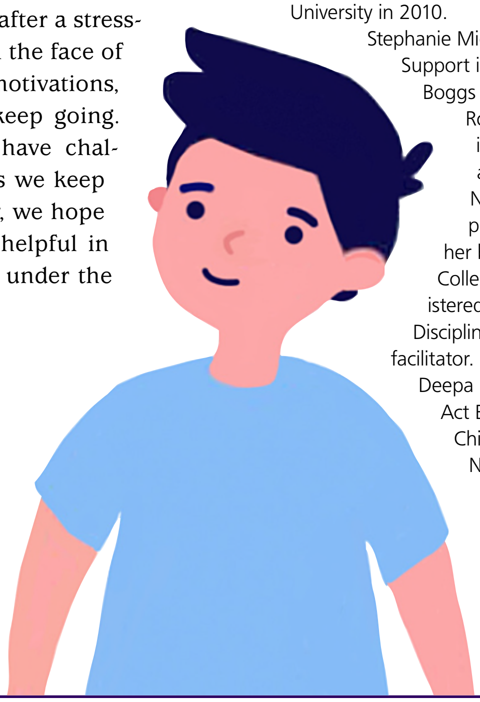
3. https://link.springer.com/article/10.1023/A:1026592305436
4. https://www.sciencedirect.com/science/article/pii/S0891422209000894
   https://www.canr.msu.edu/news/social_emotional_competence_an_important_protective_factor_part_6



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SUPPORT FOR FAMILIES : BUILDING RESILIENCE DURING TRYING TIMES

LIFECOURSE
Essentials for Parenting
www.lifecoursetools.com/lifecourse-library/foundational-tools/family-perspective

CDC'S "LEARN THE SIGNS. ACT EARLY."
www.cdc.gov/ncbddd/actearly/parents/index.html

DIVISION FOR EARLY CHILDHOOD RECOMMENDED PRACTICES (DEC RPS)
www.dec-sped.org/dec-recommended-practices

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

FAMILY VOICES/ FAMILY-TO-FAMILY HEALTH INFORMATION CENTERS
https://familyvoices.org

NATIONAL FEDERATION OF FAMILIES
www.ffcmh.org

PARENT TO PARENT USA
www.p2pusa.org

CENTER ON THE SOCIAL AND EMOTIONAL FOUNDATIONS OF EARLY LEARNING
http://csefel.vanderbilt.edu/resources/family.html

HELPING YOU COMBAT COVID-19

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COMMERCIAL AND RESIDENTIAL CLEANING PRODUCTS & SERVICES

Bantec Sanitizing is your ally in the fight against Covid-19. With efficient and affordable solutions for cleaning and safely sanitizing residential, school and business settings, Bantec Sanitizing can help you prepare for living, learning and working in a safe and healthy environment.


HOME


SCHOOL


OFFICE

Bantec Sanitizing offers a wide selection of industry-leading products for all of your sanitizing needs. In addition, we are introducing groundbreaking technological innovations that can be custom tailored for your particular specifications. Visit **bantec.store/pages/bantec-sanitizer-service** for more information.

Our products are easy for anyone to use in multiple environments to protect themselves by disinfecting surfaces they encounter throughout the day.

CLEANING PRODUCTS
www.bantec.store/collections/all

Our service provides the safest, most environmentally friendly hygiene strategy. Easy to use and implement while being efficient and cost effective.

CLEANING SERVICES
www.bantec.store/pages/bantec-sanitizer-service

EXCLUSIVE OFFER!

BANTEC DISINFECTING KIT

Easy for anyone to use in multiple environments to protect themselves by disinfecting touch surfaces they encounter throughout the day. Perfect for use between cleanings. Featuring Enviro-Pro ® products which meet the EPA's criteria for use against the novel coronavirus. Each kit contains:

- 3 gallons CleanSmart Enviro-Pro
- 1 1 oz. dispensing pump
- 1 1/8 oz. dispensing pump
- 2 each 32-oz. Enviro-Pro labeled spray bottles
- 2 each spray bottles triggers
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2021
EP GUIDE
NAVIGATING SPECIAL NEEDS RESOURCES

SELECTING A POST-SECONDARY PROGRAM IN THE TIME OF COVID-19

FACTORS TO CONSIDER

BY ERNST VANBERGEIJK, PH.D., M.S.W.

Selecting a program for your special needs child is difficult enough in the best of times. With the advent of the COVID-19 global pandemic, the decision-making is further complicated with additional health and safety factors to consider. How does one select a post-secondary program for a special needs young adult in the best of times? How does the existence of COVID-19 alter the decision-making process? What factors do parents and the young adult potentially have to consider before they commit to a post-secondary program?

Searching for a post-secondary program for any young adult is a potentially difficult process. A key concept to adopt is the notion of the process being one of joint discovery. In order for the program to be successful, the young adult needs to feel that they are a part of the decision-making process. A key point of discussion will be, what is the purpose of the post-secondary secondary program? Is it to gain job skills? Independent living skills? Social skills? A certificate in a trade? Or a college degree?

Whatever you and your young adult decide is the purpose of the post-secondary program, the ultimate goal should be that the program will result in her joining the world of work and living independently. The end goal should not be simply the receipt of a college degree or certification in a trade. What path he or she will take to be able to live as independently as possible and work in meaningful employment will depend upon your young adult's interests, aptitudes, and nature of his or her disability. There is no single guaranteed pathway to this ultimate goal. For a detailed analysis of the factors to consider when selecting a post-secondary program prior to the pandemic see (VanBergeijk, 2018).

Many people believe that getting a college degree is the only way to achieve the goal of getting a job. This is simply not true. According the U.S. Department of Education, slightly less than 1 out of 3 adults in the U.S. have a 4-year college degree or higher (Ryan & Bauman, 2016). The majority of adults in the U.S. do not have a college degree. They are able to support their families and have meaningful, fulfilling lives. The trades are having difficulty attracting young people to their fields. Many of the trades have paid apprenticeships and help young people avoid the large debt they may incur through college loans. In fact, the average age of a carpenter in the U.S. is 40.6 years old (Data USA, 2020). According to the U.S. Department of Labor, there were 1,643,900 jobs for carpenters and other construction laborers in 2019.The job growth for the next 10 years is 5%, which is faster than average (U.S. Department of Labor, 2020). The average annual salary for carpenters in 2018 was $40,573 (Data USA, 2020). Electricians also are an aging population with an average age of 41.2 years and an average annual salary of $56,808 (Data USA, 2020).

COVID-19 CHANGES THE GAME

The year 2020 will go down in the history books as the year of the COVID-19 pandemic. As of December 11, 2020, the world reported a total of 69,788,140 infections and 1,585,727 deaths. Unfortunately, the United States did not present a unified COVID-19 response. The lack of a coordinated policy is reflected in the data. The United States had the highest number of infections of the G-7 nations with 15,632,336 infections nationally, and a total of 292,382 deaths (Johns Hopkins University Corona Virus Resource Center, 2020). The number of infections and deaths are disproportional to the percentage of the population. With over 330 million Americans, we present a little over 4% of the world's population. Yet, the United States accounts for 22.3% of the infections and 18.4% of the deaths globally. The number of infections is 5.6 times greater than expected, given our percentage of the world's population. Likewise, the number of deaths is 4.6 times greater than expected, given our percentage of the world's population. The country is gripped by a third wave of infections with the number of deaths exceeding 3,000 deaths per day. It has become the leading cause of death in the United States. Current models predict that the United States will surpass 539,000 deaths by April 1, 2021 (Institute for Health Metrics and Evaluation, 2020).

IMPACT OF COVID ON PEOPLE WITH DISABILITIES

Pneumonia deaths among people with Intellectual and Developmental Disability (IDD) has been described as the canary in the COVID-19 coal mine. The percentage of deaths of people with no IDD who died of pneumonia in 2017 was 1.8%. For individuals with an Intellectual Disability, the death rate due to pneumonia was 7.8%. It climbed to 9.1% for individuals with cerebral palsy and 10.2% for individuals diagnosed Downs syndrome. The death rates from pneumonia are between 2.2 and 5.8 times greater than the non-disabled population (Stevens & Landes, 2020). Given that the COVID-19 virus attacks the lungs of many individuals who become infected, it stands to reason that we would expect higher death rates among the IDD population as a result. The death rate from COVID-19 in the State of New York for individuals with IDD as of April 2020 was 2.2 times greater than the general population. (Stevens & Landes, 2020).

In terms of COVID-19 infection and death rates among individuals with other kinds of disabilities, the disparities are also profound. Individuals diagnosed with depression, ADHD, bipolar disorder, and schizophrenia are at a much higher risk of infection and death than individuals with no mental disorder. The disparities are further compounded by gender and race. “Individuals who had both a recent mental disorder diagnosis and COVID-19 infection had a death rate of 8.5% and a hospitalization rate of 27.4% compared with 4.7% and 18.6%, respectively, among individuals with COVID-19 and no mental disorder” (Graminga, 2020).

Public health protocols enacted to protect the population have had unintended consequences for the disabled population. Individuals with disabilities are generally more socially isolated than nondisabled individuals. The need to quarantine and physically distance has only exacerbated their sense of isolation and loneliness.

UNEMPLOYMENT

The impact upon the economy has been catastrophic. Unemployment claims have reached record highs. The number of people filing for unemployment assistance has reached a record high of 23 million in May of this year. The unemployment rate rose higher in three months of COVID-19 than it did in two years of the Great Recession (Pew Research Center, 2020). Any apparent dip in the unemployment figures does not reflect an actual drop in the number of unemployed individuals. Rather, it reflects the number of people who are eligible to be counted as unemployed.

In order to be counted as unemployed, an individual must engage in a certain number of job-search related activities within the last 30 days. Many unemployed individuals have given up looking for work and are no longer counted among the official unemployment numbers. Prior to the pandemic, 8 out of 10 individuals with a disability had given up looking for work (U.S. Department of Labor, 2017). Consequently, the reported unemployment rates among the disabled are artificially low. The pandemic has resulted in a bimodal distribution of unemployment. Many individuals with disabilities were laid off in the first-round layoffs when the pandemic began.

A second group of individuals with disabilities are employed in essential services working in grocery stores, restaurants, and in day care centers. This group is faced with the anxiety of working with the public and the fear of catching the disease. The result is that a large group of people with disabilities that were laid off are driven into poverty and face food insecurity. “By the end of April, more than one in five households in the United States, and two in five households with mothers with children 12 and under, were food insecure. In almost one in five households of mothers with children age 12 and under, the children were experiencing food insecurity,” (Brookings Institute, 2020). No specific research is currently available on COVID-19’s impact upon the food security of individuals with disabilities. We can only surmise that its impact will more greatly affect this population.

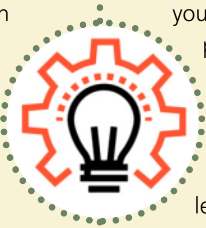
The country has been changed is multiple ways. We now wear face masks in public and physically distance ourselves from others. Hand sanitizer stations are ubiquitous. Our daily routine has been disrupted. This is the context in which families must explore and search post-secondary programs.

The operations of the program can change drastically as a response to the pandemic. Campuses have generally been open. Now students may find that their access to buildings is restricted. Nonessential buildings may be closed. Buildings in use may have a

NEXT STEPS : CONSIDERATIONS IN SELECTING A POST-SECONDARY PROGRAM IN THE ERA OF COVID-19

1. CAN MY DAUGHTER OR SON LEARN THE SKILLS REMOTELY?

There are some outstanding on-line programs available. Some students prefer an on-line environment to an in-person experience, especially those that have social anxiety or social skills difficulties. Other students have difficulty with executive functioning. Initiating tasks can be a major impediment. Without in-person supports and prompting, some of these students will fall through the cracks by forgetting to log onto a class on Zoom™ or Microsoft Teams™. Ask the on-line program you are considering how they engaged students on-line. Do they call, text, or e-mail a student immediately if they have not shown up for class? Will they help your student set reminders on their phones, tablets, or laptops?



There are certain skills that are very difficult to teach or learn remotely. Teaching independent living skills on-line can be challenge during the pandemic. It will be important to get a sense from the program how will they teach the independent living skills and what are the expectations of the family in helping with the process. An on-line program can teach cooking, skills for example, but this will require the family to supervise the shopping and cooking at home. Laundry skills can also be taught remotely, but it will require the participation of the family to ensure the young adult with a disability practice the laundry skills by doing their own laundry. Similarly, cleaning of a dorm room or apartment is easier in situ, but it can still be done at home if the family is willing and able to engage the student with a disability in learning room organizational skills while at home.

(cont.)

PHOTOS PROVIDED BY JIM ABRAHAMS

NEXT STEPS : CONSIDERATIONS IN SELECTING A POST-SECONDARY PROGRAM IN THE ERA OF COVID-19 (cont.)

2. WHAT HAS THE PROGRAM DONE TO MAXIMIZE SAFETY?

Ask the program administrators about their experience with teaching during the pandemic. What precautions have they taken? Have they had any COVID-19 cases? How did they deal with them? Be wary of any promises of safety. Listen carefully to whether or not they are following the science, and the data as well as CDC guidelines, and state and local mandates.

Many college-based transition programs have set forth community compacts that all students, including students with disabilities must abide by, if they wish to attend courses and other activities on campus. This is an agreement all students, faculty, and staff will follow during the pandemic. The most basic tenets are wearing a mask, physical distancing, and frequent hand washing. It may include agreeing to regular COVID-19 testing and the daily reporting of symptoms using a smart phone-based application (e.g. CoVerified™). Some colleges, universities, and other post-secondary transition community-based transition programs have gone even further to create “pods” or “bubbles” of students. Students in these pods or bubbles agree not interact or socialize with anyone from outside of their bubble and testing regime.

One of the most difficult parts of the compact to abide by are the guidelines surrounding not gathering in large groups. Developmentally, all college-aged students with or without disabilities are geared toward socializing. They go off to post-secondary education wanting to socialize away from the supervision of their parents. Large gatherings of young people can become super-spreader events. Community compacts frequently define the consequences of violating these guidelines. This can include immediate removal from campus and even dismissal from the college, university, or post-secondary program.

Probably one the hardest guidelines for families to follow is the inability of families to visit their student during the semester, or the ability of the student to come home for breaks. In fact, some colleges and universities have altered their semesters’ structure to eliminate vacation periods mid-semester and shorten the students’ time on campus. By visiting the student on campus or the student coming home for a weekend or short break, the integrity of the pod or bubble is compromised, potentially exposing all pod members to infection. Parents need to discuss with their student their ability to not socialize in large groups and the family’s ability to be physically separated for as long as a 15-week semester.

Other considerations involve spacing, cleaning, and the provision of personal protective equipment (PPE). What percentage of the student body will be allowed on campus? Most institutions will have conducted extensive analyses of the classroom, dormitory, recreational, and lab spaces. They will have calculated the maximum capacity for each classroom space which will have completely different guidelines than workout facilities. Ask what is the maximum capacity in the spaces your student will be studying and living in?

The cleaning of buildings, high-contact surface areas and air filtration are other important considerations when thinking about selecting a post-secondary program in the time of COVID. Most institutions have increased their cleaning schedules. Some have invested in air filtration systems, hoping to mitigate the potential spread of the virus in buildings. Others simply encouraged the use of open windows for adequate ventilation or have encouraged teaching classes outdoors, weather permitting. Finally, find out about PPE. Will the program provide the PPE and disinfecting products? Or is it incumbent upon the student to provide the PPE? Ask what happens if the student forgets, loses, or runs out of PPE or cleaning products. Does the program have replacements, or will they take the student shopping to replace these items?

3. WHAT KINDS OF SUPPORTS WILL BE AVAILABLE DURING QUARANTINE AND SHOULD THE STUDENT TEST POSITIVE FOR COVID-19?

Perhaps one of the most anxiety-provoking periods will be waiting for the COVID-19 test results for the first time. Depending upon the state and the post-secondary program, students may either need to arrive on campus with a negative COVID-19 test within a prescribed number of days; or must come to campus; move-in; get tested; and await results while in quarantine. The wait times vary from 24-72 hours currently. Students with disabilities may struggle with the isolation and the need to stay in their rooms. Residence life staff should be checking on the students regularly, seeing if they need anything. Keeping the student busy during this time period is critical and is often a joint effort between the faculty teaching classes during the day, and the residence life staff providing social and recreational activities at night and on weekends.

door monitor checking each person’s cell phone application (that he or she uses to report daily symptoms) before entering the building. If the person does not adhere to the reporting and testing protocols, or has a positive test result, they may be barred from entering the building until they are cleared by the app.

There are a number of considerations to weigh prior to selecting a post-secondary program for a student with disabilities in the time of COVID. Paramount in that selection are knowing the purpose or goal of the education; and knowing the adaptations the programs have made in response to the COVID-19 pandemic. Families will have to weigh the potential risks of the various models of education (e.g. in-person, on-line, and hyflex or hybrid) versus the benefits of a particular model or program. The student has to be comfortable with how the program is responding to the COVID-19 pandemic and with how the education is being delivered.•

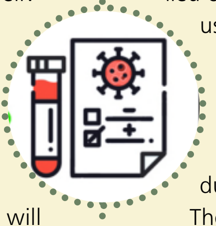
ABOUT THE AUTHOR:

Ernst VanBergeijk, Ph.D., M.S.W. is a professor at Lesley University in Cambridge, MA and is the Director of the Threshold Program which is a post-secondary transition program for students with a variety of disabilities. www.lesley.edu/threshold. He also oversees the Lesley University Threshold Alumni Center which provides life-long support for graduates of the Threshold Program. Beginning Summer 2022 the Threshold Program will be offering a 6 - week summer program focusing upon the acquisition of preemployment, independent living and social skills.

The provision of food during the quarantine period is of utmost concern to both the students and their parents. How will food be handled? Will the students go to the cafeteria and pick up their meals? Or will the meals be delivered to their rooms? How many meals will they be expected to eat in their rooms while they are in quarantine? Who will be expected to order and pay for the food? If the students are expected to order their own food from an outside vendor, will there be support available to teach them to use a food delivery service such as Uber Eats™, Grub Hub™, or Doordash™?

How the student finds out about a positive COVID-19 test result will be important to know ahead of time. Will the student find out via an e-mail or a text? Or will health services give the student a telephone call directly? Discuss ahead of time with your student what the positive test may mean and what they should do in the event they receive such news. Knowing ahead of time what kind of support they will receive from the program will help reassure the student.

Find out whether those support services will be tele-health; or moving to a quarantine facility for more direct care and supervision. It will be also important to know what is the expectation of the program that the student will go home to convalesce or stay in place to recuperate once they have tested positive. There may be different answers depending upon distance the student would have to travel in order to get home. Some students will not be able to be picked by car and driven home by their parents. Travel on public transportation will most likely be prohibited.

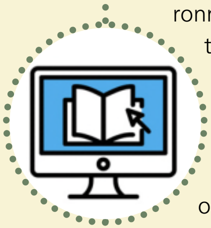


4. HOW HAS THE PROGRAM MODIFIED ITS CURRICULUM OR ITS OPERATIONS IN RESPONSE TO THE PANDEMIC?

The range of modifications can be quite vast. It can range from reconfiguring the living arrangements to changing the delivery of the curriculum. Some colleges have limited the capacity in the residence halls and the occupancy of communal bathrooms. Others have come up with unique solutions for housing, such as using local hotels in lieu of operating a residence hall. By using hotel rooms, the college or program can ensure the student has both a private room and a private bathroom, thereby limiting a student's exposure to others during non-class time.

The nature of teaching has been significantly impacted during the pandemic. How the curriculum will be delivered again varies widely. Some programs are completely remote, meaning both the faculty and the students are living and learning remotely. No one is on the campus. Other programs will offer a Hyflex™ approach. The student or the faculty member can choose to be remote. A group of students can be in a classroom sitting in a configuration following CDC distancing guidelines while the faculty member uses Zoom™ or some other platform to teach the class from her or his home. The faculty member and students will be supported by a teaching assistant who is in the classroom if there are any technical issues. Some students under this model can join the class remotely as well.

The program may also vary the delivery of the curriculum by combining portions of the semester that are virtual or on-line with a limited residential experience and in-person learning. Families must consider the benefits of social interactions with peers at an in-person program with the risk of infection versus attending a program virtually and the requisite social isolation by staying at home.



The teaching of soft employment skills is especially hard to do on-line. However, programs have had to curtail their offering of community-based internships because of the pandemic. Programs cannot maintain a pod or bubble concept and allow the students to work at an internship exposing them to the general public. However, the college or university may be able to develop work like opportunities on campus that give some exposure to a work environment and maintain the bubble or pod concept. Every person participating in the work-like environment must also participate in the testing protocol and daily reporting of symptoms. Otherwise, the protective notion of the pod will be compromised. Programs can use technology to supplement some of the skills they would otherwise learn in an internship. There are a number of software programs to teach job readiness and job skills. For example, students can explore careers using Virtual Job Shadow™. To learn customer service skills and potentially earn an industry- recognized certificate, students can look to the National Retail Foundation™ which offers a customer service course on-line. SYMmersion™ allows students to develop an avatar and go through a series of progressively more complex series of job interviews. For students who are interested in early childcare as a career, Myvirtualchild.com™ teaches students basic concepts in early childcare education.

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PROPER PLANNING SUPPORTS PEOPLE WITH DISABILITIES TO LIVE THEIR BEST LIVES

BY ALEXANDRA BAIG, MBA, CFP®

My family likes playing board games. A favorite is "Settlers of Catan." For those of you who have never played, the object of the game is to gather resources such as bricks, wood, wheat, and sheep and then combine them and use them to build roads, settlements, and cities.

The settlements and cities allow you to collect even more resources and, in turn, build more roads, settlements, and cities. It is not just about accumulating, though. You also have to be strategic about how you use your resources. Eventually, someone has built enough to reach a certain goal in order to be declared the winner. Financial planning is a bit like a game of Catan. You collect resources, use and invest them strategically to generate more resources, and eventually, you have enough to purchase your home, send your kids to college, retire, and maybe leave something to heirs. With the game of Catan, once you have mastered the basic version, there are "expansions" and "extensions." These create more complexity and allow for more players. Financial planning for a family member with a disability is a bit like playing Catan with expansions and extensions. It takes longer and is harder.

> "For people with disabilities, proper planning makes the difference between having a meaningful, quality life and living within the mediocre limits of what public benefits alone will cover."

To continue with the board game analogy, the first step in planning a secure future for your family member with a disability is describing what "winning the game" would look like.

- ***Living situation:*** *Does the person want to live by themself? With friends? With a spouse or partner? With other family members? With a pet?*
- ***Location:*** *Does the person want to live downtown or in the suburbs or in a rural location? Do they need or want to be by public transportation? Medical or therapeutic facilities? Recreational locations? Their job?*
- ***Employment:*** *Does the person expect to work? Part-time of full-time? In a paid or volunteer capacity?*
- ***Support:*** *What level of support does the person need at home? At work? When out and about with friends? To travel? To maintain health and safety? How much of this support can be "natural" and how much must be structured and paid?*
- ***Recreation:*** *What does the person like to do for fun? Does it require a budget? A particular venue? Ongoing lessons or training? A membership? Transportation? Equipment?*
- ***Community:*** *Where does the person find a place to belong? At work? In the neighborhood? With a structured social group? On a team? With a worshiping community?*

Once the person and family have a vision of adult life, the next step is to forecast the cost of each aspect of the person's desired adult life. Catan is very simple in this regard. No matter who you are or where on the game board you are, it will always take a certain number of resources in a certain combination to build a road, a settlement, or a city. Here is where we have to move beyond the scope of the analogy. In real life, the housing for a person living in the Chicago metropolitan area will cost a lot more than that for a person living in Lost Nation, Iowa (population 408 in 2018). A person, who needs 24-hour-a-day support, will have a lot higher expenses than one who needs only 15 hours a week. Someone who is highly social and very active will have more things to pay for than someone who is a homebody. Someone who has a chronic or significant medical dimension among their disabling conditions will pay a lot for health care.

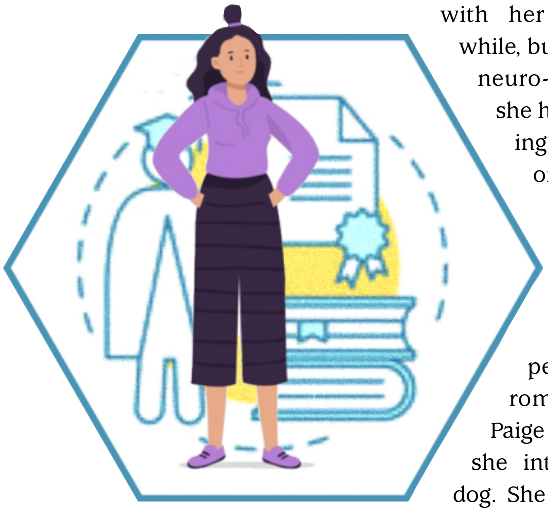
The third step is to begin to collect, manage, and utilize the resources. The basic Catan game has five types of resources: wheat, sheep, ore, bricks, and wood. If you have a settlement or city on the corner of a piece of land that produces that resource, you will collect it on certain die rolls. You can exchange one resource for another according to your location and certain formulas. You can also lose resources to the "robber" with a particular die roll. It takes bricks and wood to make a road; bricks, wood, wheat, and sheep to build a settlement, etc. In every case, you need to make strategic choices to maximize your store of resources and then combine the right resources in the right ratios to build as much as possible.

People with disabilities have three basic categories of resources that will support them as adults.

- ***Income from work.*** *Many people with disabilities can and want to work. Although it may require more planning, they can spend, save, and invest their income from work just like anyone else.*
- ***Government benefits.*** *People with disabilities may qualify for various kinds of Social Security benefits as well as Medicare, Medicaid, and support services funded by Medicaid waivers. These benefits generally have financial as well as medical eligibility requirements, so it is important to understand the interaction among work income, accumulation of savings, and eligibility for these benefits.*
- ***Family supplements.*** *Some people with disabilities will be able to fully pay for their adult lives with their income from work and the public benefits for which they are eligible. But in many cases, there will be a gap that families will need to fill both while the parents are alive and after they are gone.*

People with disabilities need to strategize to maximize each category and combine the categories in the best way to fund their life vision. In most cases, the entire family needs to be part of the discussion and the calculations to make sure that family resources are stretched to do the most for each member. Let us look at a concrete example.

PAIGE'S BEST LIFE: THE SCHOOL YEARS



Paige is a young woman with a developmental disability. She has the capacity and the desire to work – at least part time – and her family supports her in this goal. Paige expects to continue living with her parents for a while, but just as with her neuro-typical siblings, she has a goal of "having her own place" one day. Paige is very social, so she wants to live with one or more friends as housemates or, perhaps, with a romantic partner. Paige loves animals, so she intends to have a dog. She does not expect to drive, but she likes to be active, so she wants to live near public transportation, where ride-share drivers are plentiful and not far from the downtown district. Her faith congregation and her recreational soccer league are important communities for her, so she wants to be within easy commute of services, practices and games.

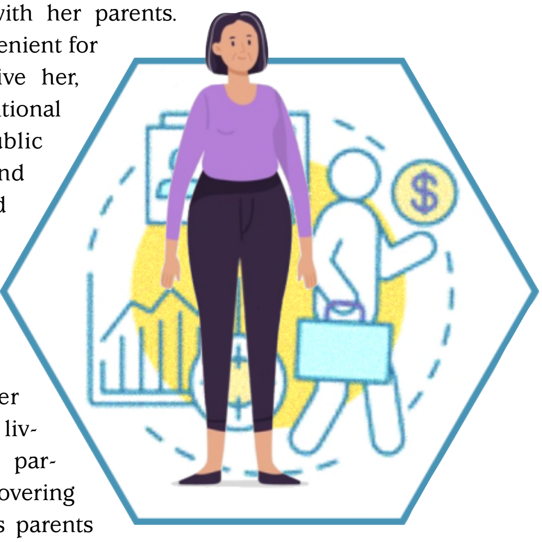
When Paige begins at age 14-and-a-half to work towards her eventual transition from high school to adult life, she and her family make sure that her transition plan includes real-life work experiences, where the wages are processed through regular payroll, and FICA taxes are deducted. Paige also starts her own micro-business, walking and sitting dogs for her neighbors. Paige's parents help her file her tax returns both to claim her refunds from her W2 jobs and to pay self-employment tax on her dog-related earnings.

When Paige is 18, her parents accompany her to the local Social Security office to apply for disability benefits. Paige brings medical evidence of her disability and explains to the agent how her disability limits her capacity to work. She also explains how she will begin paying room and board to her parents as soon as she begins to receive her benefits. This is so that she can receive the maximum SSI for which she is eligible. Paige is approved to receive Supplemental Security Income (SSI) due to her disability. Her payment is reduced for her work earnings, which she reports to Social Security every month, but not for her live-at-home status, because she pays room and board.

As a child/adult child with a disability, Paige can continue to be covered under her parents' employers' group health insurance plan. However, she applies for Medicaid anyway, since she expects to use adult-disability-support services after she ages out of high school; and these services require Medicaid eligibility, since they are funded by Medicaid waivers. Paige and her parents decide that Paige does not require legal guardianship but will use "supported decision making" and have her parents as her financial and medical agents via powers of attorney.

As Paige moves through her school's transition program, she shifts away from academics towards more paid work experience in keeping with her goal of finding a part-time job in the community, once she ages out of school. Based on her part-time paid W2 work, and her dog-related self-employment, Paige earns six Social Security credits before she turns 24. She then qualifies for Social Security Disability Insurance (SSDI) on her own work record. Because of that income and her work income, Paige's SSI is reduced. After 24 months of receiving SSDI, she also qualifies for Medicare. Her group health coverage under her parent's insurance remains the primary payer with Medicare as secondary and Medicaid as tertiary. Paige also opens an ABLE (Achieving a Better Life Experience) account so that she can save and manage a portion of her own money in a way that will not eliminate her eligibility for SSI and Medicaid.

PAIGE'S BEST LIFE: AN ADULT NOW



At age 30, Paige moves into an apartment with two of her best friends. She now has to pay rent and her share of the utilities as well as the personal expenses she paid while still living with her parents. Since it is less convenient for her parents to drive her, she also has additional expenses for public transportation and ride shares. She and her family calculate that Paige's part-time work income, plus her SSDI and SSI will cover 60% of her total independent living expenses. Her parents commit to covering the balance. Paige's parents chose which expenses to cover so that Paige can maintain the maximum SSI payment for which she is eligible.

Once Paige leaves school, she and her parents apply for one of the Medicaid waivers programs in her state. The waiver pays for 10 hours of a job coaching per month through a local disability-service agency. Paige's job coach takes over the school's former role in helping Paige to learn new skills at her job as well as to talk to her employer about reasonable accommodations, particularly in high-stress times such as when Paige gets a new supervisor. The waiver also provides for 20 daily living support hours per month. Paige's support worker helps her with tasks such as paying her bills on time, budgeting with her housemates, maintaining a healthy diet, and managing appointments with health care providers.

When Paige is 37, her parents reach their full retirement age and file for their Social Security retirement benefits. Since Paige's disability started before her age 22, she is eligible for so-called Disabled Adult Child (aka Childhood Disability) benefits, based on her parents' work records. Her parents considered filing early so as to start Paige's additional benefit earlier but decided against this course of action, since they were both still working. Paige's DAC/CDB benefit, together with her own SSDI benefit and her work income now make her ineligible for SSI, but she maintains her Medicaid, and thus her waiver-funded services, as a member of a "special group of former SSI recipients". Paige's parents continue to cover the gap between what Paige receives from work and Social Security and Paige's actual living expense.

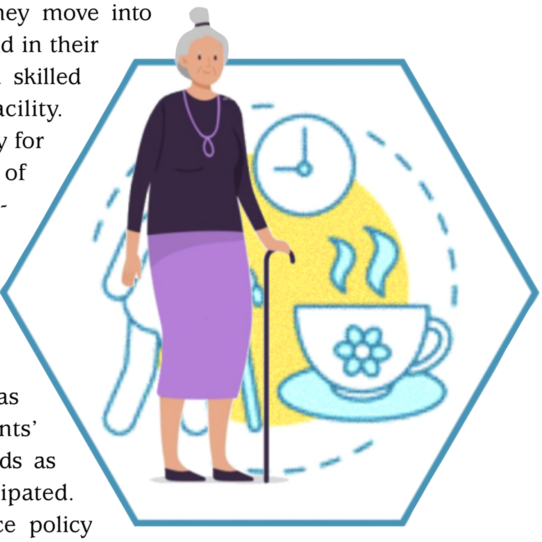
Paige's parents are aware that they will need to continue to supplement Paige throughout her life, but also that they, themselves, will need to use some of their assets in retirement. They work with a financial planner to calculate the amount that they will need, in addition to their Social Security, to cover their post-retirement living expenses, the additional travel they hope to do, their medical expenses (expected to rise faster than average inflation), and their potential long-term care needs. The parents also want to leave money to Paige's older sister and their grandchildren. If there is enough money, they would also like to leave a small bequest to the non-profit that has provided support for Paige as an adult. The parents work with a special needs attorney to update their wills. Since they had not yet done so, they create a special needs trust with Paige as the beneficiary. They name themselves as trustees and Paige's sister as a successor trustee. They let other family members know about the trust in case anyone wants to include Paige in their bequests.

PAIGE'S BEST LIFE: GETTING ON

Paige's parents realize that Paige will be eligible for an additional amount of Social Security as an Adult Child survivor, but also that Paige herself will retire from work at some point. They will need to fund her Special Needs Trust to continue to cover Paige's unmet needs once they are gone. The family works with their special needs financial planner to decide which assets to use for Paige's parent's retirement, which to use to fund Paige's special needs trust, and which to leave to their heirs without disabilities, with a goal of minimizing taxes and complications in each category. In order to reduce the possibility that a market downturn near the time of their death would leave Paige's trust underfunded, they purchase a survivorship (second-to-die) life insurance policy to cover a portion of the amount they calculate that they will need to fund Paige's trust. They also purchase some long-term care coverage for themselves so they will not deplete too much of their assets if they need extended nursing home care. Although Paige's sister lives in another state, they keep her up to date on the family's documents and plans.

Once the main financial and legal aspects of the family's plan have been implemented, Paige's parents continue to monitor it with their advisors. Their financial planner adjusts the plan's forecasts, based on the actual performance of their investments. Their attorney reviews their trust documents whenever Social Security makes a major adjustment to the regulations governing eligibility.

Paige's parents live into their early 90's before they are each unable to manage some of their major activities of daily living without help. They begin to draw on their long-term care coverage to pay for their home-health aids, freeing both Paige and her sister from worry. As their need for support increases, they move into assisted living, and in their final year, into a skilled nursing facility. Although they pay for some of this out of pocket, the long-term care insurance minimizes the hit to their assets.



Once the second parent has died, the parents' estate plan unfolds as they had anticipated. The life insurance policy pays out to Paige's special needs trust. Certain other financial assets are allocated to the trust and others to Paige's sister with the particular bequest to the non-profit agency. By this time, both Paige and her sister are close to retirement and Paige's sister, in particular, is relieved to know that there are sufficient assets in Paige's special needs trust both to provide for the increased daily living support Paige requires to remain living with her housemates and her dog in her own apartment and to cover any of Paige's own long-term care needs so that she is not restricted to living in the type of facility that Medicaid alone will fund.

Catan is challenging, but it is just a game and there is no penalty, beyond losing face, for the player that either mismanages resources or fails to plan ahead. For people with disabilities, however, proper planning makes the difference between having a meaningful, quality life and living within the mediocre limits of what public benefits alone will cover. •

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Alexandra Baig maintains her own national financial planning practice, Companions On Your Journey, and also acts as the Benefits Specialist for Clancy & Associates, a Chicago-based law firm focusing on special needs planning. Alexandra has an MBA from the University of Michigan and her CERTIFIED FINANCIAL PLANNER™ designation and is a member of the Academy of Special Needs Planners. In particular, she is well-versed in the government benefits available to people with special needs and the rules governing them. Her goal is to help people with disabilities and their families make the most of public and private money to live the life they chose.

2021
EP GUIDE
NAVIGATING SPECIAL NEEDS RESOURCES

PEOPLE WITH DISABILITIES WANT TO WORK

SOCIAL SECURITY INCENTIVES MAKE IT SAFER TO TRY

BY ALEXANDRA BAIG, MBA, CFP®

You have an acceptable job. It does not challenge you at all and the pay is only so-so, but is it is pretty much guaranteed until your retirement if you just maintain the status quo. One day, your boss comes to you with a proposal.

The company is launching a new product. There has been some market research, but it is anyone's guess whether the product will actually succeed. You have the background and knowledge to – potentially, anyway – sell the product to customers. The company has a created a sales position for this new product and the job is yours if you want it. The work would be much more challenging and interesting than what you are doing now, and you have the opportunity to make much better money and advance further within the company, but the position will pay commission only, with no base salary. If you fail, there is no guarantee that you could return to your old position. Oh, and because you would be a 1099 employee, you will not have health insurance. Would you take the risky new position or not? I expect many of us would hesitate, at least.

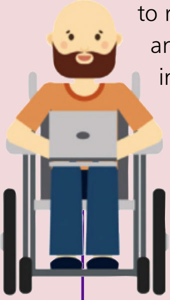
This dilemma is somewhat analogous to the one faced by people who, sometimes after much effort, have managed to qualify for Social Security Disability Benefits, either Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) and who would like to start or return to work. Many have the skills and the drive to be successful at work. If they are successful, they will have a much more interesting livelihood and very probably more income. However, for many, their physical, mental or emotional capacity to work is as yet uncertain. What if they achieve a certain level of success at work and begin to earn enough that they lose their eligibility for cash benefits as well as their Medicare or Medicaid health insurance, but then are unable to maintain that level of earning – and, even worse still, have to apply all over again to regain their benefits?

Social Security's Work Incentives are designed to mitigate this risk. They are designed to encourage beneficiaries to take the risk of trying employment with the reassurance that they can maintain their benefits while they try. This article will discuss the details and applications of these Work Incentives.

GETTING TO WORK : SOCIAL SECURITY WORK INCENTIVES AND EMPLOYMENT

THE TICKET TO WORK

Everyone, who receives Social Security Disability benefits, has a "Ticket to Work", which (though it used to be an actual paper ticket that arrived in the mail) is now simply an electronic designation. Ticket holders first choose an employment network, either their state's vocational rehabilitation office, or a private-sector agency. The employment network then provides a suite of services, including skills assessment, assistance with resume writing, job search and application, education on how to request reasonable accommodations, and guidance on and planning for the impact that work income will have on the Ticket holders' public cash and health care benefits. The employment network is paid by Social Security at no cost to the beneficiary. As long as a Ticket holder is making what the Social Security Administration calls "timely progress," the Ticket to Work, the person is not subject to continuing disability reviews. Timely progress is defined quite specifically and depends on the career stage of the ticket holder. If the person needs further education in order to become employed in a field for which they have the capacity, then timely progress is measured by completing courses of study and obtaining certificates or degrees. If the person goes straight to work, then timely progress is measured by the person reaching and sustaining certain levels of earning.



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GETTING TO WORK : SOCIAL SECURITY WORK INCENTIVES AND EMPLOYMENT (cont.)

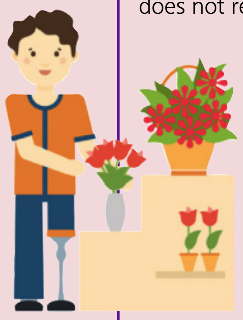
EARNED INCOME EXCLUSION AND STUDENT EARNED INCOME EXCLUSION

When an SSI beneficiary returns to work, the first $65 ($85 if they have no unearned income) of their earned income is not counted. Only one-half of the remaining income is counted and reduces their SSI benefit. For example, take a person, receiving the 2021 maximum SSI benefit of $794, who begins to work and earn $905/month. The first $85 and then half of the remainder of their work income do not count, leaving $410 (($905-$85)/2). The beneficiary's SSI is thus reduced by the $410 and they continue to receive $384/month. Full time students under 22 have an earned-income exclusion of $1,930 up to $7,770 in a calendar year. Note that unearned income is treated less favorably. Only $20 may be excluded; the rest reduces the beneficiary's SSI dollar for dollar.

ACHIEVING A BETTER LIFE EXPERIENCE (ABLE) ACCOUNTS AND PLANS TO ACHIEVE SELF-SUPPORT (PASS)

SSI and Medicaid beneficiaries may have a disincentive to work because, despite the income exclusions discussed above, if they save some of their work income it becomes from the month following receipt a "countable resource." To maintain SSI and Medicaid eligibility, a beneficiary's countable resources may not exceed the very minimal threshold of $2,000. Countable resources are basically cash and cash-equivalents like investments. ABLE accounts and PASS both provide approved methods to except cash and investment assets from being counted as resources. ABLE accounts are special tax-advantaged accounts available to people who have a Social Security level of disability (whether or not they are actually receiving benefits) that started before the age of 26. Generally, the accounts can receive up to $15,000 of contributions per year, but workers can contribute an additional amount that is the lesser of their work earnings or $12,490. ABLE account funds are not countable as a resource for SSI and Medicaid eligibility purposes. If the ABLE account balance exceeds $100,000 and the amount over $100,000 plus the person's other countable resources exceeds the $2,000 threshold, SSI payments are suspended until the account balance declines. Medicaid eligibility is not affected. ABLE account funds can be withdrawn tax-free to cover any Qualified Disability Expense, a category that includes not only expenses, directly related to the account holder's disability, but also to things like education, technology and daily living expenses.

A PASS is a much more focused vehicle for saving money for a certain period of time. A person with a disability, who wants to save money to pay for goods or services that will increase their earnings capacity, can do so with a PASS. The PASS is like a business plan that explains the amount and nature of the expenditures, the time period over which they will occur, and the way that the expenditures will enhance the person's capacity to earn. A worker with a disability might use a PASS to pay the cost of tuition for a certificate or degree program, to engage in a certain type of work-related skills training, or to purchase the equipment to freelance or start their own business. Income contributed to a PASS is not counted as income when calculating eligibility for SSI and Medicaid eligibility, or for calculating the size of the worker's SSI payment, and funds held in a PASS are not countable resources for the duration of the plan. To maintain the exclusions, the PASS must be used to fulfill the purpose for which it was created.



IMPAIRMENT RELATED WORK EXPENSES (IRWE)

IRWE are expenses that can be deducted from a person's earnings before Social Security counts those earnings to determine the ongoing eligibility for benefits. To qualify as IRWE, the item or service to be expensed must be necessary because of the person's disabling condition(s), be necessary for the person to work (although its use need not be limited to the work environment) and not covered by insurance of any kind. The cost of a service animal, medical or assistive technology, adaptive clothing, or special transportation along with the co-pays for medications and visits to physicians or therapists, are all examples of IRWE. Once approved by Social Security, IRWE can be deducted each month that they are applicable. Large-ticket, one-off expenses can be deducted either in the month paid or spread out for up to a year.

EMPLOYER SUBSIDY

An employee with a disability may require reasonable accommodations that decrease their productivity relative to a co-worker who does not require those accommodations. If the accommodation(s) can be quantified by the employer and accepted by Social Security, the value of that accommodation can be deducted before Social Security counts those earnings to determine ongoing eligibility for benefits. If an hourly employee is allowed 60 minutes more of break time during the day than their co-workers, then the monthly value of the deduction is 1 x the hourly wage x days worked in the month. If an employee with a disability is only required to complete four units of work to others' five, or is only expected to cover four out of five of the position's major responsibilities, then the value of the subsidy deduction is one-fifth of the employee's monthly compensation.

CONTINUED PAYMENT UNDER VOCATIONAL REHABILITATION OR SIMILAR PROGRAM

People with disabilities who work and then lose eligibility for cash benefits either because they are deemed to have improved

Returning to the hypothetical situation that opened our article, suppose instead that your boss comes to you with a better proposal. Suppose instead of being commission-only, the new position has a base salary that will continue until you know how well you can handle the job, but on top of that base you will earn bonuses if you do well. Moreover, your health insurance will continue and you will have the option to return to your old job if the new one proves impossible. I expect you, like most of us, would be inclined to take the risk. In a similar fashion, Social Security work incentives encourage people with disabilities to work, knowing that they have a safety net to fall back on. •

medically or because they have turned 18 and fail to meet the adult disability criteria, may continue to receive cash payments if they are either participating in a program for vocational rehabilitation or receiving other similar services, including services under an Individualized Education Program (IEP) or the Ticket to Work. Payments will continue until the person completes or exits the program or until Social Security determines that the program is no longer enhancing the person's capacity to work.

CONTINUED PAYMENT UNDER SECTION 1619(A)

A person, who receives SSI and starts working, will see their work earnings reach the Substantial Gainful Activity (SGA) threshold before the SSI reduction formula has reduced the benefits to $0. For example, the SGA level for 2021 is $1,310/month. Suppose a worker's earnings reach $1,315. If the SSI reduction formula, including the earned income exclusion, is applied to this level of earnings, the worker would have ($1,315-85)/2 or $615 of countable income. Since the maximum SSI payment for 2021 is $794 under 1619(a), then they will still be eligible to receive the $179, remaining after the reduction formula is applied despite having exceeded the SGA threshold.

UNINCURRED BUSINESS EXPENSES

People with disabilities who opt for self-employment can deduct the value of expenses that are incurred and paid by a third party from their net self-employment income if those expenses would have reduced countable net income had they been incurred and paid by the self-employed worker. For example, if a parent buys an adult child with a disability a fabric printer so that the adult child can start a business such as custom-designing t-shirts, the machine would be an unincurred business expense. Another example would be if a local non-profit provides office space to a worker with a disability at no charge.

TRIAL WORK PERIOD (TWP) AND THE EXTENDED PERIOD OF ELIGIBILITY (EPE)

When an SSDI beneficiary first starts work, Social Security compares the earnings to a Trial Work Level threshold. For 2021, this amount is $940/month. The worker can accumulate up to nine months in which they exceed that threshold in a rolling 60-month period. It does not matter whether they exceed the threshold by $1 or $5,000. Once the worker has completed the ninth months, they have completed Phase 1 of going off their SSDI benefits. They then enter a 36-month Extended Period of Eligibility when they still qualify for a cash benefit, but only receives that benefit if their work income is below the threshold of Substantial Gainful Activity (SGA). The SGA threshold for 2021 is $1,310/month ($2,190 if blind).

MEDICAID CONTINUATION

Many people with disabilities are not as concerned about losing their cash benefits as they are about losing their Medicaid, which underwrites both health care and support services (via Medicaid waivers, which fund most of adult disability services in most states). Workers, who once received SSI along with their Medicaid and subsequently begin earning at a level where they are no longer eligible for either SSI or Medicaid, are able to continue their Medicaid as members of a "Special Group of Former SSI Recipients", enshrined in section 1619(b) of the Social Security regulations. Workers who never received SSI may use Medicaid Spend-Down in some states. This means that Medicaid will only count the income left over after the person has paid for necessary health and support services. In other states, workers can direct their excess income to a so-called Miller Trust and income thus directed will not count for Medicaid eligibility. Finally, workers with disabilities who have income above the Medicaid threshold have the option of "buying-in" to Medicaid for a modest monthly premium.

MEDICARE CONTINUATION

Workers, who became eligible for Medicare after receiving 24 months of SSDI benefits and who subsequently work enough that they no longer qualify for SSDI, may still maintain their Medicare eligibility for at least 93 months from the start of their EPE. Workers who want to sustain Medicare beyond that point, but are not yet 65, or do not have enough work credits, have the option of buying into Medicare, although that can be expensive. The cost of the Medicare buy-in may be offset by one of the Medicare savings programs.

UNSUCCESSFUL WORK ATTEMPT

If a worker with disabilities succeeds in exceeding the Substantial Gainful Activity threshold, but is unable to sustain that level of work for at least six months, and the work income decreases or ceases due to either the disabling condition(s) or to the removal of special conditions, such as the presence of a job coach or reasonable accommodations, then that period of time is considered an unsuccessful work attempt. Earnings during an unsuccessful work attempt will not be used to deny renewed or ongoing eligibility for disability benefits.

EXPEDITED REINSTATEMENT

If a worker receiving SSDI successfully completes their TWP and EPE and subsequently stops receiving cash benefits, but within five years must reduce work or stop it altogether due to the same disabling condition(s), they can request that their benefits be reinstated without the need to file a new application. Note that a person with a disability, who receives SSI, does not actually lose their eligibility. Rather, their income from work may reduce their payable SSI to $0 for a month or a series of months. However, if they are reporting their income and it drops to level where, according to the reduction formula SSI would be again payable, the payments will resume.

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Coronavirus.org

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MENTAL HEALTH CARE FOR INDIVIDUALS WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITY (I/DD) DURING THE TIME OF COVID-19

2020. Any other year would not be a sentence on its own. At this point, it could be used as an epithet. Or a vulgarity. Certain dates convey a sense of trauma: December 7th, 1941. 9/11. All of us this year have shared the burden of trauma with losses and difficulties that range from mild to indescribable.

BY BENJAMIN A. MARGOLIS, M.D.

While data on the pandemic's effect on individuals with I/DD is lacking, we can see that the mental health impact in the general population is immense. Rates of anxiety, depression and overall stress have increased,[1] and is greater among caregivers[2]. In my practice, and anecdotally among colleagues, we observe a familiar pattern: a slow and steady increase in difficulties brewing since March of 2020. While there is light at the end of the tunnel as the Pfizer and Moderna vaccines are ramping up production, there still is a long road ahead until life resembles pre-pandemic freedom.

Initially in March 2020, with shutdowns implemented, the novelty and immediacy of the changes helped many with coping. Through the Summer in many areas, like in New York where I practice, restrictions were able to ease while case numbers were decreasing and regular programming was able to resume to some extent. As the cold has returned and with it required restrictions on activity, for many individuals, coping skills are strained.

In the mental healthcare field, we have been ramping up to meet the needs of communities and have innovated to be able to deploy care remotely. We have been able to use existing technologies to provide support via telephone and video in ways never before permitted, in spite of many years of technical feasibility. While the needs for mental healthcare among the I/DD community has never been greater, telemedicine has expanded access to help meet that need.

If an individual has never before received mental health supports, there can be some trepidation with regards to making the decision to seek mental healthcare. Fortunately, while psychiatric care may need in-person visits, depending on the circumstances, many problems can be addressed without an individual having to take the risk of presenting to an office in-person. In the setting of psychotherapy and non-pharmacologic behavioral healthcare, telemedicine can be preferable as both the care provider and the individual can see each other unmasked, improving communication.

In spite of expanded availability due to telehealth, it can still be daunting for a parent or caregiver to find care that is sensitive to people with developmental disabilities.

> “In the mental healthcare field, we have been ramping up to meet the needs of communities and have innovated to be able to deploy care remotely. While the needs for mental healthcare among the I/DD community has never been greater, telemedicine has expanded access to help meet that need.”

WHERE CAN I GO FOR HELP?

Finding care in the area, especially in rural communities, has historically been a significant challenge. Individuals now may be able to be seen at their residence, and in some circumstances may be able to be treated by a specialty care center in other states. Thanks to regulatory changes in response to COVID-19, geographic barriers to care have in some circumstances been eliminated.

When local care Is best, that geographic challenge remains. Finding a local mental health provider has historically been a significant challenge for many families. As many people who have tried to find mental healthcare may have already deduced, specialty training in I/DD is not currently a required part of psychiatric residencies, and many mental health providers have not had experience working with the I/DD community. While difficult, it may not be impossible to find a provider in your area.

The community may have a hidden gem in a therapist or psychiatrist that works privately, and word-of-mouth networks can be a valuable means of finding mental health resources in your area. The range of resources is diverse, depending on your insurance, your location and your community. The power of Google can’t be underestimated, with searches such as “specialty mental health care for intellectual disability near me,” and related terms, which can link you to community organizations and clinics nearby with resources. There is no magic or hidden resource, it sometimes simply takes the virtual equivalent of elbow grease and patience to find a provider.

In times of crisis, the need may be quite significant and the barriers can seem overwhelming. Depending on the severity of the needs, the delay to an appointment can be an issue. While 911 and emergency services are available if safety is ever a concern, depending on where you live, you may be able to access crisis management services for individuals with I/DD. **The START program**, which stands for “Systemic, Therapeutic, Assessment, Resource and Treatment” is a national initiative providing comprehensive crisis management tools for behavioral needs among individuals with I/DD. There are with START programs or program partners currently in 14 states, including New York, Texas and California. The START program can be linked to through www.centerforstartservices.org/locations .

For outpatient psychotherapy and psychiatric care, **The National ARC** website links to individual ARC chapters, many of which provide listings and links to local providers and specialty care centers. It can take a few clicks, but starting at https://thearc.org/find-a-chapter is an excellent launch point. If there are no links directly from your local ARC, a call instead to the local chapter can help connect you.

The National Association for the Dually Diagnosed is an organization based in Kingston, NY dedicated to improving mental healthcare for individuals with I/DD. A list of their certified mental health providers is available at http://thenadd.org/certified-clinicians , and if there is no listing for your state or community, the NADD can be reached via email or phone and may be able to provide resources closer to home.

For the most comprehensive list of available mental health resources nationally, **SAMSHA, the Substance Abuse and Mental Health Services Health Administration** website, has a care locator that can quickly provide a large number of resources by zip code, at https://findtreatment.samhsa.gov . This is a list of both I/DD and non-I/DD resources. It is a good idea to ask about the provider’s comfort and experience with working with I/DD and accommodations with telemedicine or in the waiting areas if going from the SAMSHA database.

Local community mental health centers, often state-funded or local nonprofit-run, have also become a de-facto hub for care of people with developmental disabilities nationally, and many have providers who are experienced with and passionate about caring for individuals with I/DD. In areas where specialty care centers dedicated to the care of I/DD are not available, many community mental health centers have therapists and psychiatrists familiar with the needs of the I/DD community and waiting rooms which can accommodate vulnerable individuals and their staff. A call to the front desk staff may not provide an adequate answer to this question, but a conversation with an intake coordinator or manager may provide a name and an appointment with an experienced and ready provider. Better still, many of these centers are now providing telehealth services preventing the challenge of waiting room tolerance and COVID-19 risk.

ONCE YOU HAVE YOUR APPOINTMENT

Once an appointment is made, the work can begin. It may take some time for a mental health specialist to understand a problem.

Having as much information available at the ready will make sure they can begin to help. Recognizing and accurately diagnosing psychiatric disorders in I/DD requires more information than making the same diagnoses in the general population. If you can be ready to help provide information and observations, you can make a huge impact in quality of care and helping to target treatments to the right problem.

THINGS TO BRING WITH YOU (VIRTUALLY OR IN PERSON) TO YOUR FIRST BEHAVIORAL HEALTH APPOINTMENT

First and at the top of the list, after introducing the individual, introduce the mental health provider to everyone the individual is working with. This can be a list with phone numbers, and the people who know the individual best should accompany the individual to the appointment, if possible. One great thing about telemedicine is that members of the care team can attend an appointment from different physical locations. An individual's care community can be so tight-knit and so familiar to those within it, that it can be easy to forget that such understanding is not a priori, and us providers will need to get to know the lay of the land.

> "In my own practice, I present problems with mood and behavior as a puzzle. Working in the general population, there are an equal number of pieces and different complexities, however when we are working with people with I/DD, everyone in the team has a piece of the puzzle that can help us see what's happening."

Even when a psychiatrist is savvy and works regularly with people with I/DD, they may not be familiar with the culture of an agency or group home providing services, what staff fulfills needed roles, or how nursing participates in care. Regulations may vary from state to state, and a psychiatrist may not be familiar with some of the rules and regs guiding how care is provided, especially if the individual lives in a different state. Different agencies sometimes interpret rules differently and have different internal policies regarding medications and behavioral supports available, so helping us become familiar with the care team and the agency culture can be of great benefit. Contact information for, and even better, participation of, the person's house or agency behavioral clinician (in the setting of group homes and agencies utilizing them) can help the sometimes disparate psychological and psychiatric teams integrate a care plan.

For individuals who live at home with their families, or alone with supports, the need to get to know the care team and family dynamics are the same, and the need for comprehensive medical information remains.

A list of all the individuals' different physicians and care providers can help us coordinate care when needs are complex. When utilizing pharmacologic therapies, it is essential that the right hand knows what the left hand is doing, so-to-speak, and communication can prevent medication errors or interactions.

In my own practice, I present problems with mood and behavior as a puzzle. Working in the general population, there are an equal number of pieces and different complexities, however when we are working with people with I/DD, everyone in the team has a piece of the puzzle that can help us see a clear picture of what's happening. If an individual doesn't use words to communicate, then it's our job to find ways to listen and understand. The other people that have pieces to a puzzle need to be available to us. In residential settings, it is often imperative to have contact information for the house managers, the staff members who know an individual best along with family contacts so everyone involved in treatment can participate.

For individuals whose families are a large part of their lives, they can often hit the ground running since a dedicated parent or caregiver can provide invaluable care coordination simply by providing clear and accurate information. A dedicated parent can help make sure we have the information we need to be able to determine when medication is needed, when separate medical evaluation is appropriate, and can help us understand what a behavior is communicating.

For initial psychiatric or neuropsychiatric appointments, a current and accurate medication list will be essential. A complete medical, surgical and developmental history will allow us to understand someone's physical needs. If medications were prescribed for mental health treatment in the past, a list of prior trials, when the medications were prescribed, and at what doses, will be very helpful. Understanding someone's sleep habits, dietary needs, motor problems and even their bowel regularity will not only help us understand an individual better, but also will help us monitor and avoid any potential side effects to medications.

A copy of any prior IEPs, behavior plans, neuropsychological testing and medical records, prior EEGs and brain imaging (copies of head CTs and brain MRIs) can help us understand differentiate between causes of behaviors and can help us see a comprehensive picture of an individual.

In the setting of psychotherapy and nonpharmacologic behavioral care, while medical records may not be part of that person's care to the same extent, the same team-based, multidisciplinary set of information will be helpful when available to the therapist. When someone is able to communicate easily with words or has a less significant intellectual disability, they may be able to utilize resources that are targeted to the general community without any difficulty, however community and team involvement can nonetheless be utilized.

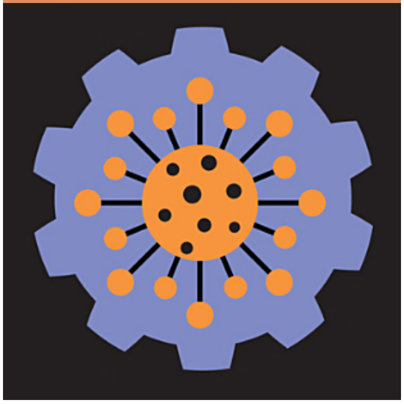
SELF-CARE, RESOURCES AT HOME:

With the first wave of cases and implementation of COVID-19 related restrictions, families and provider agencies adapted schedules and switched to home or remote programming to maintain a sense of regularity. Utilizing online or remote day programming with familiar staff helped mitigate feelings of loneliness and isolation. Many of the same tools and techniques that were used in coping with the first wave of shutdowns will still apply as we hunker down for the long Winter ahead, awaiting our vaccines.

Resources for individuals in the home setting for self-care and mindfulness are numerous and varied as to be impossible to cover in a single article. Nonetheless, as a template for coping during this time, families and caregivers are the best resources and the greatest experts on the needs of an individual, second only to the individual themselves.

Maintaining regular sleep can be very helpful. The natural tendency when spending more hours indoors and when individuals aren't getting up for work or activities is to late-shift, where people sleep later and later throughout the day and fall asleep later and later at night, leading eventually to day/night reversal which can create anxiety and drive behavioral dysregulation. Limiting screen time 2 hours or so before bed can avoid reinforcing this pattern, and therapists and behavioral clinicians can help with sleep hygiene, often without the need for pharmacotherapy[3]. If the person can maintain some physical activity with video game systems such as Wii, or dancing to music or appropriate YouTube videos, there are clear benefits in mitigating anxiety[4]. Adapting schedules and maintaining a sense of routine can be among the most powerful tools in managing the problems of adapting to COVID-19 restrictions.

> **"Families and caregivers are the best resources and the greatest experts on the needs of an individual, second only to the individual themselves. Adapting schedules and maintaining a sense of routine can be among the most powerful tools in managing the problems of adapting to COVID-19 restrictions."**



CONSIDERATIONS AMONG THOSE DIRECTLY AFFECTED BY COVID-19

Among individuals who have been directly affected by COVID-19, either from being ill themselves or from the loss of loved ones, there are additional considerations of trauma.

Loss and grieving can be experienced and expressed in a variety of ways, and can lead to poor mood, decreased appetite, changes in sleep and emergence of old problematic behaviors. Getting used to the absence of a loved one can take up to a year, and for individuals who have special difficulty adapting to change, recovering from these losses may take even more time. Seeking help from a professional can help to differentiate normal grief and bereavement from complicated grief that may need pharmacologic supports, and can help provide personalized adapted tools to move through grieving[5].

Among those who have been ill with COVID-19, there may be some cognitive or neurologic changes from the virus itself in the form of strokes caused by the disease, periods of hypoxia or lack of oxygen, in addition to the fact that evidence is emerging that COVID-19 can affect the brain itself,[6,7] independent to the potential trauma of a COVID-19 hospitalization. When an individual with I/DD is hospitalized with COVID-19, there are now protections in place to ensure that hospitals allow caregivers or designated staff or family to accompany them during the stay. Even with this consideration, the trauma of illness itself, coupled with the unfamiliar situation of being in isolation rooms cared for by medical teams in gowns, masks and whose expressions can't be read, can add to the trauma of hospitalization.

The possibility for post-traumatic stress disorder among individuals with I/DD after illness with COVID-19 is very real, and earlier treatment can help mitigate some of the long-term symptoms. Nightmares, new anxiety and avoidant behaviors, resurgence of old problems and disruptions in sleep can be some of the most obvious and earliest responses to the trauma of a COVID-19 admission.

With a team approach, those of us who provide mental health care for I/DD can help the community move through and recover from this impossible time. We stand at the ready.•

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2021
EP GUIDE
NAVIGATING SPECIAL NEEDS RESOURCES

INCLUSION IS ESSENTIAL, EVEN IN REMOTE LEARNING!

BY DEBBIE ESPOSITO AND LAUREN AGORATUS, M.A.

Many school districts are now using remote learning or hybrid models combining remote and in-person learning. This can be difficult for all students, but students who need additional supports often find it even more challenging. Families of students with disabilities may be struggling with distance learning and how their children can be fully included, even in a remote environment.

INNOVATE TO CREATE: In order to provide services to children with learning differences, parents and the school districts must work together. The team should come up with creative ways to educate the student.

INSTRUCTIONAL SUPPORTS IN REMOTE LEARNING THAT FACILITATE INCLUSION

Department of Education Guidance: Guidance from the US Department of Education[1] clarifies that, if a child is in an inclusive placement during in-person learning, they should still be in an inclusive placement during remote learning. School districts must ensure that Individualized Educational Programs (IEPs) are followed and that each student receives a free, appropriate public education (FAPE). Each eligible student with a disability must be provided the special education and related services identified in the student's IEP developed under the Individuals with Disabilities Education Act (IDEA), or a plan developed under Section 504. Further, COVID-19 *has not* changed a student's right to services in the Least Restrictive Environment (LRE), even though it *has* changed how general education systems operate. School systems need to determine how they will maintain LRE for each student depending on the way that they deliver services to students without disabilities, which will look different from district to district.[2] For this to happen, families and schools *must* communicate and work together to make sure appropriate services are provided.

RIGHTS REMAIN: COVID-19 *has not* changed a student's right to services in the Least Restrictive Environment, even though it *has* changed how general education systems operate.

Access to instruction: Students with disabilities must be able to have access to instruction that will enable them to receive FAPE. US ED guidance clarifies that schools and districts may use IDEA funds to ensure that students with disabilities have access to the equipment and connectivity they need to participate in their education. The district can conduct a needs assessment to determine the number of students that will require the district to provide devices and/or internet access in order to access remote education. It is important to consider the technological needs of all students, including those with learning disabilities, assistive technology needs, and language barriers. Some students require additional in-home services to access a free, appropriate public education (FAPE). These services may include but are not limited to nursing for students who are medically fragile or paraprofessionals (aides) for students who may have difficulty accessing the alternative options for learning being offered. Many districts contract these services out to private agencies.

Some of these agencies may say that they are not contracted to go into students' homes, only school. Per IDEA, the district must provide the services listed in the IEP even if they must contract another agency to do so. For some students, assistive technology may allow them to access instruction. Families and other IEP team members must work together to decide which in-home services are appropriate. Finally, some families of medically complex children may request that *no* aides or nurses come into their home during COVID for health reasons. This is an IEP team decision, which includes the parents, so the family and school must work together to benefit the student.

Supports for Students with Learning Disabilities: There are many ways to provide supports for students with learning differences. FAPE needs to be determined on an individual basis. While the delivery of services in a certain way might work for one student, it might not work for others. Again, the parent and the district must work together. The team should come up with creative ways to educate the student. For example, American Sign Language interpreters or captioning provided for deaf and hard of hearing students may meet the student's needs. The teacher can read aloud classroom material to make it accessible for a visually impaired student. Teachers can also provide more inclusive opportunities by taking advantage of group activities with peers and assigning roles. For students who have difficulty following directions, students can either ask the teacher to repeat (unmute or post in chat), or for pre-recorded videos rewind and playback. To facilitate access to instruction, many schools are providing devices such as Chromebooks, or tablets, and internet access or "hot spots". Bookshare (www.bookshare.org/cms/#content) is free to students with visual impairments, dyslexia, or other print disabilities. Students can have online access to the school library database. Modification of the curriculum will allow students to complete assignments and projects at home. A one-to-one aide can assist in implementing many of these suggestions *(For more information, see the video "Instructional Assistants in the Virtual Classroom" at* https://www.youtube.com/watch?v=1s1GVZBmvns&feature=youtu.be).

Adapting the IEP: As noted earlier, it is important for families to know that the COVID-19 pandemic has not changed the individual student's right to receive FAPE in LRE under federal law. The Office of Special Education Programs has reminded state and local education agencies that no matter what primary instructional delivery approach is chosen, they and IEP teams remain responsible for ensuring that FAPE is provided to all children with disabilities. As a result, COVID-19 and health and safety concerns that come with it require school districts to determine how to maintain each individual student's right to be educated in the least restrictive environment under the current circumstances.

Supports to Help All Students: We know that everyone does this to the best of their ability, but this is a new day and age due to COVID and we might not see how routine noises can be a major distraction for students. Parents working from home should be aware that their own phone conversations, zoom meetings, and email "ping" notifications could be distracting to students in hearing distance.

The following tips are best practices for remote learning and can be helpful for maximizing inclusion and participation in remote settings:

1. ELIMINATE DISTRACTIONS

The student should have a designated work area. The workspace should be uncluttered. If possible, have the workspace in a quieter part of the house. Make sure the student has all supplies on hand before the virtual class begins so there will not be any interruptions once class begins. If there is more than one child, stagger their schedules if possible. If possible, mute all phones, electronics etc.

TIME TO LEARN: Students may benefit from working for various shorter periods of time with breaks, rather one long session. A visual timer, such as the one from timetimer.com *(above)*, is a great tool. Some students may benefit from visual checklists or schedules *(left)* to organize their day. If they can choose the colors it is great to have them take ownership in the process.

2. "CHUNK" THE ASSIGNMENT

This is a teaching strategy the teacher could be using. The teacher will break the information down by topic or "chunks". This is because some students learn better by learning information in steps, rather than all at once. The teacher can then review each section, before moving to the next one. Teachers will be doing this in accordance with the IEP. (*For more information on "chunking" in remote learning, see 4 Tips For Content Chunking In e-Learning at* https://elearningindustry.com/4-tips-for-content-chunking-in-e-learning.)

3. FREQUENT BREAKS

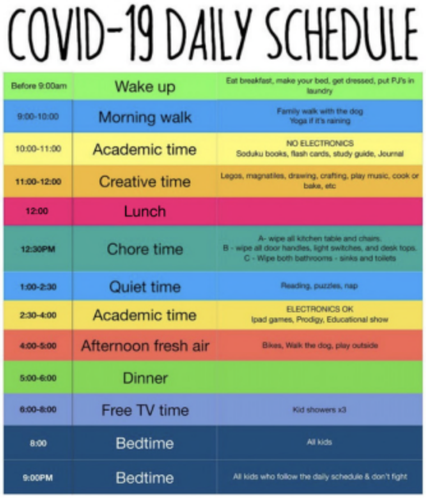
Some students may need more frequent breaks than others. If the student is in a virtual class, h/she could even just stand for a bit instead of sitting the entire time. Make sure students ask for breaks appropriately (type into the chat, or raise their hand) before they act out. Parents can reinforce breaks by praising when they "use their words". Breaks between activities can be taking a short walk (even inside), getting a snack or drink, etc. Over time, students may be able to tolerate longer times learning online and need less breaks. Proactively giving students regular breaks avoids disruptive behaviors

4. ADJUST LENGTH OF TIME IF NEEDED

Some students may have difficulty attending for long periods of time. Students may benefit from working for various shorter periods of time with breaks, rather one long session. Again, students may be able to focus for longer periods of time once they get more used to the remote learning environment. A great tool is a visual timer (www.TimeTimer.com) that students can use to work on projects for a set period of time. Students should be reinforced for the amount of time they work, even if just 5 minutes. As students progress, the time can be increased. Parents and teachers can discuss this as a way to facilitate an inclusive placement for a student who has difficulty attending to virtual instruction for lengthy periods of time. If the student can set the timer, it gives them responsibility for ending their own break and removes the responsibility from the parent.

5. CHANGE THE SCHEDULE

Most students benefit from having a daily schedule so they know what to expect. If possible, have the child work on the most difficult subject first, so as the day goes on, they'll be able to tackle easier subjects later even if they are tired. However, if a child does better in the afternoon, schedule difficult topics then rather than in the morning. Some students may benefit from visual schedules (color-coded) or checklists to organize their day. Again, if they can choose the colors it is great to have them take ownership in the process. For more information on setting up a schedule, see http://blog.parentsquare.com/covid-19-tips/tip-9-help-families-set-up-daily-schedules-for-remote-learning.



COVID-19 DAILY SCHEDULE

Before 9:00am	Wake up	Eat breakfast, make your bed, get dressed, put PJ's in laundry
9:00-10:00	Morning walk	Family walk with the dog Yoga if it's raining
10:00-11:00	Academic time	NO ELECTRONICS Soduku books, flash cards, study guide, Journal
11:00-12:00	Creative time	Legos, magnatiles, drawing, crafting, play music, cook or bake, etc
12:00	Lunch	
12:30PM	Chore time	A- wipe all kitchen table and chairs. B - wipe all door handles, light switches, and desk tops. C - Wipe both bathrooms - sinks and toilets
1:00-2:30	Quiet time	Reading, puzzles, nap
2:30-4:00	Academic time	ELECTRONICS OK Ipad games, Prodigy, Educational show
4:00-5:00	Afternoon fresh air	Bikes, Walk the dog, play outside
5:00-6:00	Dinner	
6:00-8:00	Free TV time	Kid showers x3
8:00	Bedtime	All kids
9:00PM	Bedtime	All kids who follow the daily schedule & don't fight

6. GIVE SPECIFIC FEEDBACK

When feedback is given, the goal is for the student to use the feedback to improve themselves or improve the way they accomplish the task. That means effective feedback to students must be clear and specific. Feedback from teachers and families must also be given in a way (e.g., mode of communication) so that the student can understand. Instead of using the usual "good job", it is more reinforcing to say "I like the way you… (had your book open, or lined up items to count etc.) For more information on feedback in remote learning, go to article on distance learning from the TIES Center at https://tinyurl.com/y53tb3mr

RELATED SERVICES IN A REMOTE SETTING AND INCLUSION

Guidance on related services during COVID-19: IDEA ensures continuity of special education and related services to children with disabilities. If a school district is unable to provide related services as stated in the IEP, students may be entitled to compensatory services.[3] Compensatory services can be provided as "make up" sessions for missed services not provided by the district in accordance with the IEP. Find a tracking form and sample compensatory services letters here https://spanadvocacy.org/covid-19-resource-page

What are Related Services?: Related services can include, but are not limited to, any of the following:[4]

- *speech-language pathology and audiology services*
- *interpreting services*
- *psychological services*

TIMERS IMAGE COURTESY TIMETIMER.COM; SCHEDULE IMAGE © JESSICA MCHALE PHOTOGRAPHY

- *physical and occupational therapy*
- *recreation, including therapeutic recreation*
- *early identification and assessment of disabilities in children*
- *counseling services, including rehabilitation counseling*
- *orientation and mobility services*
- *medical services for diagnostic or evaluation purposes*
- *school health services and school nurse services*
- *social work services in schools*
- *parent counseling and training*

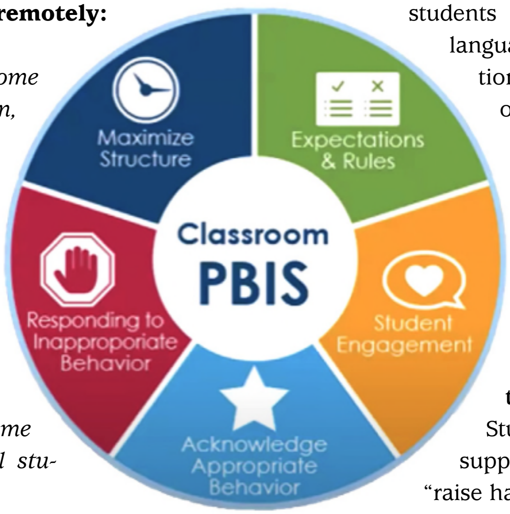
Other lesser-known related services include sensory integration (SI) (provided by a specially certified Occupational Therapist), and social skills. Some students are sensory "seekers" (i.e. need stimulation like movement) while others may be sensory "avoiders" (e.g. loud noises, bright lights etc.) SI activities can start in preschool and continue as needed up to transition. SI can be provided virtually in the same manner as OT.

Note that mental health services, such as counseling and psychological services, are also included under the related services section of the IEP. The need for these services has increased due to the pandemic. Also, note that there are related services for parents.[5] This means that services for parents can be written into the IEP as well. These could include education about the child's diagnosis, learning to use the technology that children are using, or family counseling.

Remote Related Services: In providing related services remotely, the starting point is the IEP. Begin by reviewing goals and the student's needs, taking into consideration the complexity of the needs and disability. As a team, ask "how can this student be included?" Families can work with the members of the IEP team to identify goals that can be addressed at home. The intervention must include a realistic implementation plan that takes the child's environment and accommodations into consideration.[6]

How Related Services can be best provided remotely: Best practices for remote related services must:

- ***Address access:*** *Beyond technology* ***access****, some students may need captioning/audio description, different color/contrast, etc.*
- ***Orient students:*** *Student* ***orientation*** *ensures that they have the tools and skills needed to participate in inclusive sessions.*
- ***Have a routine:*** *Students will follow the* ***routine*** *of entering the session, turning the camera on, and mute microphone.*
- ***Set expectations:*** *All students need to know* ***what to expect*** *in the session.*
- ***Be consistent: Consistency*** *in having the same day/time/length of sessions will help include all students.*
- ***Encourage participation:*** *Encourage* ***participation*** *by using tools like polls so everyone does the activity together.*
- ***Use the child's strengths:*** *A reading* ***strength*** *could be hyperlexia and could benefit from oral/written prompts to enhance comprehension and communication with peers, thus enhancing inclusion.*
- ***Embed into daily activities:*** *Practice during* ***routines*** *(e.g., bedtime, grooming, bathing, dressing, etc.) Daily routines such as mealtime can be reinforcing: for speech, name things on the table; for OT, use utensils (or adapted utensils), etc.*



Inclusive remote related services: Some tips for providing related services remotely to include children are:

- *Students participate in a group, instead of alone.*
- *The therapist can list supplies needed beforehand and students with similar abilities can do a project together. Alternatively, teams could include students with a range of strengths and challenges.*
- *The speech therapist can do a breakout room during remote instruction.*
- *Therapists can create breakout room groups for OT/PT activities, which can be done together.*

Mental Health: COVID and school closures have been traumatic for many students. Students' lives have been disrupted and some have lost friends or family. Racial incidents, bullying, and suicides have all increased. There must be a focus on social/emotional learning for students. Remote social/emotional and mental health related services could be provided remotely. Some ideas could be:

- *To move in-school counseling appointments online.*
- *Teachers can reach out to parents about detecting early warning signs.*
- *Encourage virtual social opportunities. Virtual social opportunities could include workout groups for sports teams, virtual debate teams, clubs, etc.*
- *Schools and families may turn to outside resources, like the Children's System of Care in some states.*

Behavioral Supports: PBIS and remote instruction: Positive Behavioral Interventions and Supports (PBIS) will help address challenging behaviors and facilitate inclusion. Some ways this can be accomplished successfully remotely include to:

- **Maintain school-wide behavior expectations:** All students will benefit from the consistent language of the school's PBIS expectations or values across physical and online settings.
- **Consider behavior expectations during common activities:** Behaviors must be maintained for all remote activities whether they are teacher-led instruction, independent work, one-on-one work, or small group activities.
- **Think about behavior expectations during remote learning:** Students need to know if they are supposed to answer orally or mute, "raise hand" virtually, stay on camera, and use of the chat function. Given the challenging circumstances under which students are learning, avoid overly punitive or over-intrusive discipline rules/behavior expectations.
- **Use direct instruction:** For direct instruction, teachers must explain the information rather than just post which could leave some students out or feeling frustrated.
- **Differentiate support:** Just like an in-person class, behavioral supports must be individualized based on the needs of the student. Staying on camera, for example, may be distracting for a

child, so that is something the IEP should discuss. A Positive Behavior Intervention (or Support) Plan can proactively avoid challenging behaviors.

What parents can do…: Finally, here are some tips for families to help students with remote related services:

- **Reinforce what the related services providers are doing:** If a child receives a related service, if it's not reinforced until the next session, it's like going to the gym once a week and expecting to get in shape.
- **Advocate for parent training when needed:** For example, nonverbal children may use ASL, communication devices, etc.- remember parent training can be included as a related service in the IEP.
- **Make sure the child is included in the same activities as the rest of the group:** Again, if the child is in an inclusive in-person environment, the same must hold true for remote learning.
- **There are parent resources for fun speech/OT/PT activities:** Examples of fun speech activities for parents to do with children can be found under Resources. There is also information for PT/OT resources as well.

COVID-19 has brought many challenges to schools and families. Parents and schools must partner to make sure that remote learning and related services are satisfactorily provided to include all students.

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3. https://www2.ed.gov/policy/speced/guid/idea/memosdcltrs/qa-covid-19-03-12-2020.pdf
4. https://www.parentcenterhub.org/iep-relatedservices
5. https://www.wrightslaw.com/advoc/articles/support.bardet.htm
6. https://www.apta.org/patient-care/public-health-population-care/coronavirus/pediatric-and-school-based-pt

REMOTE CONTROL : PROMOTING INCLUSION WHILE ENGAGED IN DISTANCE LEARNING

SUPPORTS TO HELP ALL STUDENTS
https://iris.peabody.vanderbilt.edu/module/c19/cresource/q1/p07/#content

EDUCATING ALL LEARNERS
Resource Library Search Subject/Grade/Disability
https://eala.wpengine.com/resource-library

STRATEGIES FOR FAMILIES TO HELP WITH SPEECH AT HOME
https://leader.pubs.asha.org/do/10.1044/5-strategies-to-help-families-act-as-speech-and-language-coaches/full

AMERICAN OCCUPATIONAL THERAPY ASSOCIATION
Using OT in home routines
www.aota.org/-/media/Corporate/Files/Practice/back-to-school/Distance-learning.pdf
Using IEP OT goals at home
www.aota.org/-/media/Corporate/Files/Practice/virtual-services/Embedding-IEP-Goals-Home-Activities-Routines.pdf

SOCIAL EMOTIONAL LEARNING IN REMOTE ENVIRONMENTS
https://www.cde.state.co.us/cdesped/selremotelearningresources

FUN SPEECH, OT, & PT ACTIVITIES FOR FAMILIES
Speech
https://sites.google.com/sjcoe.net/parent-resources-sjcoe-special/learning-resources/speech-language?authuser=0
OT/PT
https://sites.google.com/sjcoe.net/parent-resources-sjcoe-special/learning-resources/occupational-therapy?authuser=0

REMOTE MENTAL HEALTH FOR SCHOOLS
www.ravemobilesafety.com/blog/managing-men'tal-health-remotely-for-k-12-schools

MANAGING BEHAVIOR AT HOME
www.parentcenterhub.org/behavior-athome/

TRACKING BEHAVIOR FOR REMOTE INSTRUCTION
https://ncsi-library.wested.org/resources/486

INCLUSION: RELATED SERVICES IN A REMOTE SETTING: Video
www.youtube.com/watch?v=5pRf4I7uBNU

INSTRUCTIONAL SUPPORTS TO FACILITATE INCLUSION IN REMOTE LEARNING: Video
https://www.youtube.com/watch?v=Ie9Tf5nmh3A

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EP MAGAZINE: THE JOURNAL FOR SPECIAL NEEDS FAMILIES AND PROFESSIONALS

RARE DISEASES

12 TIPS AND RESOURCES FOR PARENTS

BY TAMMY NEARON

My daughter, Taylor Nearon, was diagnosed with MCAD at the age of 18, but it took over five years to receive the official diagnosis.

Mast cell activation disease (MCAD) is a rare condition where the body produces too many mast cells within various organs, or the mast cells do not function properly and become overactive. Taylor's mast cells were within normal range but did not act or operate correctly, which caused symptoms of swelling, hives, nausea, and anaphylaxis.

During Taylor's final months, she asked me to continue the fight on behalf of other MCAD patients. My daughter helped start the Super T's Mast Cell Foundation (see About). Taylor passed away in my arms on September 28, 2017, after a brave battle with MCAD.

"Mommy, don't forget me," Taylor said.

ALL ABOUT TAYLOR

Three months after Taylor Nearon's death, Super T's Mast Cell Foundation officially became a reality. It is the first nationally-recognized nonprofit 501(c)(3) offering financial resources for patients and families impacted by mast cell diseases. Currently, there are over 4,000 known cases of mast cell diseases in the United States. The Foundation carries on its mission, fueled by Taylor's brave fight against mast cell diseases, and the boundless love between a mother and a daughter.

Before receiving the rare diagnosis, Taylor was a varsity soccer player, ran track, volunteered in the community, and spent time with her friends, family, and puppy Baxter.

"She was known for her speed when she played sports. We joked that we were going to get her a cape. When she got sick, we would say, 'Super T got this,'" said Tammy.

Before receiving this rare diagnosis, Taylor was devoted to her sports teams, her studies, and lived a "normal" teen life. She was a scoccer and track standout in high school. She volunteered as much as she could. When she wasn't playing, she could be found helping out within her church, lifting childrens' spirits in the hospital, and serving in the local food pantry.

After her diagnosis, Taylor spent most of her senior year completing coursework through Cyber School. Upon graduation

SUPER T HEROICS: Taylor went from working out 3-5 times a week to stay in shape to a girl requiring tubes to keep her alive. In 2015, she had an anaphylactic reaction caused her to lose pulse for 5 minutes and required CPR by a police officer and her mother.

PHOTOS PROVIDED BY TAMMY NEARON

RARE EXPERIENCE : TWELVE TIPS FOR IDENTIFYING AND ACCESSING RARE DISEASE RESOURCES

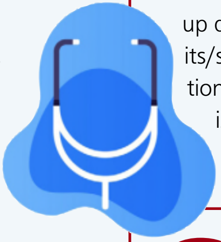
As a parent, it's overwhelming to know where to begin on the journey of locating services. There are so many questions like where do I even start, what resources are available, and what is my child eligible for? Through my journey with Taylor, I kept copious notes and found support in various places. Here are 12 tips that will hopefully help parents with a child with a rare disease:

1. Reach out to your county and state to check eligibility for various programs offered such as supplemental insurance. Most times, parents are not aware their child may be eligible for additional health insurance coverage known as secondary insurance through their state. Secondary insurance helps to offset co-pays and may offer the medical waiver program. This program is useful for visiting nurse needs, adaptive appliance and equipment needs, home modification, and more. Be sure to check your state's eligibility. Each waiver has its own age requirement and possibly a wait period.

2. If your child has nutritional needs such as formula feeds via a feeding tube, look into WIC Programs. Based upon eligibility with supplemental insurance and certain waiver programs, your child's medical formula or other nutritional needs may be covered. When there is a nutritional risk, meaning the existence of a medical based or dietary based condition, WIC Programs are very useful. Examples of medical-based conditions include anemia (low blood levels), or being underweight.

3. Durable equipment coverage is an often-overlooked need. Before spending out-of-pocket dollars, research what your primary and if eligible, secondary insurance will cover. Some items covered include wheelchairs, blood sugar monitors and strips, infusion pumps and supplies, hospital beds, pressure reducing support devices, nebulizers and nebulizer medications, walkers, etc. Various medication assistance programs exist and sometimes it's a matter of locating the program that meets your child's medication needs. Such programs are: Prescription Hope, RX Outreach, Partnership for Prescription Assistance Program, and Patient Assistance Programs sponsored by Pharmaceutical Manufacturers.

4. Search for foundations related to your child's diagnosis. A variety of foundation programs offer grants to help with incurred medical expenses, travel expenses or home modifications, etc.



5. Ask the medical institution where your child receives care how they can help. In some instances, they may offer parking waivers based upon the number of visits per month. Parking costs add up quickly when there are frequent visits/stays. Ask if they offer transportation assistance. Some healthcare organizations offer this service for patients involved with their complex care programs.

6. Address the mental aspect of the rare condition for both the age- appropriate child and parent(s). I found when my daughter was diagnosed with a mast cell disease as an adolescent, it was crucial she have someone to speak with about concerns she was facing at the time and how the diagnosis would impact her life going forward. My daughter did not want her condition to define her, she wanted coping skills. She learned beneficial mindful techniques which she found useful when trying to integrate her education,

(cont.)

from Upper Merion High School in 2015, she was accepted to every college she applied to, but had to relinquish all of her acceptances and scholarships due to the debilitating health challenges introduced by MCAD. In July 2015, Taylor and Tammy went to Minnesota to visit the top mast cell specialist, Dr. Lawrence Afrin, to seek answers. They eventually found Dr. Fidler at Abington Hospital, whom Tammy praised for saving Taylor's life at the time by starting her on continuous IV Benadryl.

While dealing with mast cell disease, Taylor's empathy and compassion grew for others who were suffering with a rare and under-recognized disease. She wanted to make changes so patients and caregivers didn't have to feel alone, unsupported, or fearful about paying bills. To move her dream of a foundation forward, Taylor developed ideas to provide opportunities for patients to receive grants which would help to offset living and medical expenses. Her hope was to alleviate some of the financial burden associated with fighting this disease. This was the beginning of Super T's Mast Cell Foundation.

Today, Super T's Mast Cell Foundation carries on this same mission, creating awareness and education surrounding mast cell diseases around the world.

"This is an underrecognized community of patients. When people support patients of the mast cell disease community, it shows they are not forgotten," said Tammy. "Every day, I miss my baby girl. But I know this was her dream, her passion. I keep going because she kept going through more than I can even imagine." •

A GREATER GOOD: Taylor Nearon runs in her Junior year of high school; Super T's Mast Cell Foundation began Taylor's dream. The compassion and empathy she demonstrated towards others is what fueled the creation of this foundation.

social and medical parts of her life. These skills also helped when Taylor was faced with further health obstacles. As a parent, I found having a therapist helpful to learn not only coping techniques, but also ways to deal with my PTSD that occurred due to my daughter having a cardiac arrest. It is okay to have your own set of life skills and mindful techniques that will be useful on your child's rare disease journey. You have your own set of worries and concerns. Self-care is critical to remember and maintain.

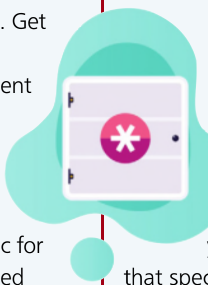
7. Create a support team. Once you have a diagnosis for your child, make a list of family, friends, community, and medical staff who will need to be on the "team." From the community aspect, if your child is in school, what is needed from his/her teacher and school? Yes, a detailed 504 Plan is key, but this goes further. We found it useful to speak with staff individually explaining the magnitude of my daughter's rare disease diagnosis. This was a great time to educate about the condition and how it impacted my child. You are your child's best advocate and this is an opportunity to educate those around your child.

Every condition impacts everyone differently. Communication is key. Additional community involvement went as far as educating our ambulance service and local police of her condition. Unfortunately, there were frequent ambulance calls. Because of advanced education on our part, this was helpful when treatment was required. Our local police placed a specific notification in relation to our address and my daughter's condition. This information will pop up, should there ever be an emergency call for your address. You may never need to call an ambulance or need police, but it is beneficial to make them aware in advance, should they have questions. Your child's needs can be tweaked over time. Establishing a line of communication proved very useful for us.

The friends-and-family team is there to help with food shopping, walking the dog, sitting with you over a cup of tea or a family game night to offer distraction. It is okay to ask who would like to be on the "team." This will change over time and that is okay! Right now, how could a friends-and-family team help you? We found having help to grab groceries every other week and walking our dog when there wasn't nursing coverage, was helpful. Also, while a bit time-consuming, create a terminology list. The team needs to understand what terms are being heard for the first time.

Finally, your child's medical team. In the rare disease world, there is a multifaceted approach to each child's medical needs. Who are each of your child's medical specialists? Create a list with their contact information, i.e., email, phone numbers, fax numbers, as well as the office managers and nurse managers point-of-contact information. There may be moments you have frequent conversations with the nurse manager. We found, in most instances, they were able to contact our daughter's doctor quicker than leaving a message. Show them (and really, everyone on your team) kindness and respect. The specialists have more than one patient, so try to have reasonable expectations.

8. Document everything. Get a good old-fashioned notebook and document everything pertaining to your child's condition. Even after you receive a diagnosis, keep taking notes. Some parents transfer the handwritten notes to a Word doc for better readability or if/when they need to email something to medical specialists. Do what works for you, but document everything (description of symptoms/date/time/etc.) by writing it down. Take pictures or videos where it will assist with written documentation. If you are able to note the "before" activity and the "after" response, this is beneficial information when determining a child's possible condition. The term "rare" is what makes diagnosing the challenge. Yes, it's time- consuming, but walking into your child's appointment with information will help the specialist paint a fuller picture of your child's health rather than relying on verbal examples from memory. Make a note of medications and your child's response to them. Over time, responses to medication may change, and having notes on any peculiar or different responses is useful information. From experience, once we started coming to appointments with documented information, specialists were able to start putting puzzle pieces together. This approach was useful when medications created adverse symptoms not otherwise seen in the mast cell patient community. Keeping notes allowed us to identify certain medications that could not be taken together and had to be spaced out further than the normal duration.



9. Communicate with your child's specialist. Have your questions or concerns written down beforehand. Keep a separate datebook/notebook strictly used for appointments. It helps keep things more streamlined so when you need to recall information from previous appointments, you have it at hand. If there are multiple specialists on the team, it is imperative to understand they each play a role and can only speak for themselves. Be open and honest with your child's treating physician in regards to his or her specialty. Rare diseases often have multisystem involvement with overlapping symptoms which may cause confusion among medical professionals, patients and parents. If you're seeing your child's cardiologist, bring questions pertaining to his specialty, his line of care, or symptoms your child may be exhibiting for that specialist to answer. Working as a team with your child's specialist will be helpful. Your child's physician may be helpful, should there need to be an appeal with insurance. They will be able to provide medical support explaining the need for particular medication needs and practices for insurance purposes. We had several appeals, and each time our medical team had to provide necessary medical support during the appeal process.

10. Research organizations and factual information from trusted medical sources pertaining to your child's rare disease. It is important to ensure articles are peer reviewed and not opinion based. Is the article based upon a case study or data gathered from a population? We had used a particular article to base a series of questions and possible testing probabilities and came to discover it was not grounded in actual peer reviewed information. Actually, the article was funded by a particular organization which provided a very biased approach for care. Look to join organizations relating to your child's rare disease. Social media offers various platforms which are very useful. Many online resources exist and may offer another level of support. Again, when joining any platform, be sure to evaluate the information being offered. It's okay to share personal experience, but remember, each case is different.

11. If your child's rare disease has them in the hospital often, like it was the case for my daughter, having the following information in a folder was always useful: signs to be placed on the hospital room door, i.e., scent-free zone, chemical-free zone, perfume-free zone. Also, a list of your child's current medications, doses, and times-per-day received, along with your pharmacy's phone number, and your child's protocols outlined by their medical team. The attending hospital team should be in contact with your child's medical team about protocols and plan of action. For us, it was helpful to bring our log of triggers, reactions and/or symptoms. We found when dealing with a rare disease, having as much tangible information on hand for medical staff to read and see was helpful in treatment plans.

12. Providers need resources, too! Physicians who are willing to learn about your child's rare condition will need factual and science-based information to gain an understanding. Consider sharing information you have discovered yourself. (This is for those medical professionals who are not familiar with the rare disease or condition impacting your child and family.)

FURTHER READING : RARE DISEASE RESOURCES

GLOBAL GENES
www.globalgenes.org

RARE DISEASE FOUNDATION
https://rarediseasefoundation.org

NATIONAL ORGANIZATION FOR RARE DISORDERS (NORD)
https://rarediseases.org

RARE DISEASE LEGISLATION ADVOCATES
https://rareadvocates.org

NATIONAL INSTITUTES OF HEALTH
www.nih.gov

EVERYLIFE FOUNDATION FOR RARE DISEASES
https://everylifefoundation.org

ABOUT SUPER T'S MAST CELL FOUNDATION

After receiving a medical diagnosis of a rare condition in 2015 known as mast cell disease, Taylor Nearon began framing her dream of what would become this foundation. Dealing with Mast Cell Disease firsthand and gaining an understanding of the complexities associated with the term "rare," Taylor wanted to make a change. She wanted patients and caregivers to never feel alone, unsupported or fearful of how to pay bills. To ensure this, Taylor intentionally provided opportunities for patients to receive grants to offset living and medical expenses. Today, Super T's Mast Cell Foundation carries on this same mission, creating awareness and education surrounding mast cell diseases around the world.

- *Attendee of 2019 NIH Rare Disease Conference*
- *Member of Patient Worthy*
- *Donated $1,000 worth of baby monitors to Abington Jefferson-Health*
- *Donated more than 250 masks to the mast cell patient community*
- *Creation of Arielle Davis Grant to be awarded once a year to a patient battling a mast cell disease*
- *In 2020, Pennsylvania House Resolution No. 1034 recognizing October 20thas International Mastocytosis/Mast Cell Disease Awareness Day*
- *Received grant from Upper Merion Community Assistance in support of the Superhero Showdown Race*
- *Launched Wisdom Wednesday – a discussion about comorbidities, patient highlights, and other topics of interest.*
- *Created Patient Involvement Committee*
- *Medical Advisory Council expanded*
- *Introduced "Super T's Quarterly Newsletter"*
- *Launched new website,* **www.supertmastcell.org**
- *Raised over $20K in combined virtual events: Virtual Purse Bingo and the 5th Anniversary Celebration of the Superhero Showdown Race.*

Remember: There are over 7,000 rare diseases affecting more than 25 million Americans. It breaks down to one in 10 Americans who suffer from rare diseases and greater than half are children. •

ABOUT THE AUTHOR:

Tammy Nearon is the President of Super T's Mast Cell Foundation. Her daughter, Taylor Nearon, founded the nonprofit organization with the hopes to educate, inspire, and improve the lives of those living with a mast cell disease. After her daughter's death, Tammy has continued to carry out the missions that her daughter created. Today, Tammy happily resides with her dog Baxter, in King of Prussia, PA. As an advocate, Tammy enjoys involving herself with the foundation and connecting with others.

2021
EP GUIDE
NAVIGATING SPECIAL NEEDS RESOURCES

THRIVE IN ISOLATION!

RESOURCES FOR PEOPLE WITH VISUAL IMPAIRMENTS OR OTHER DISABILITIES

BY CHRISTINA LLANES MABALOT
AND JEM LLANES MABALOT

A multitude of challenges hampers us who are living with a disability. We seek out tools and resources to combat the physical, mental, emotional, and social hurdles we face every day. Then, in 2020, came the bombshell of COVID-19 that left everyone in consternation. Not only does the coronavirus continue to devastate those who are directly infected, but the fear of its further spread has closed off the world through quarantining and social distancing. The events that unfolded last year have posed to our community one of the most monumental obstacles yet: isolation.

A recent conversation with a relative who is also visually impaired demonstrated the true nature of this crisis. After several months of staying at home due to COVID-19, my relative's family decided to brave the outside world. They took the kids to the park. She described a beautiful Carolina fall day blessed with warm sunshine, mild breezes, and brilliant bursts of orange, red, and scarlet leaves.

For the first time in forever, their two young children freely frolicked in open spaces while greeting strangers, also out with their own families and pets. Although they were cautious and practiced social distancing, fresh air away from home gave them a taste of the physical freedom they enjoyed, pre-COVID. On the drive home, as the family sat quietly appreciating their outing, the effects of the preceding months of isolation suddenly became poignant. The kids asked, "Mama, are you sure it was okay to sit on the bench?" and "Dad, was it okay to hold that branch?" and "Mama, can we really run again through the field and walk across the bridge over the pond?" It became clear that the kids were really asking questions relating to isolation: is it really okay to be out? Are we not going to get sick or get into trouble by not staying home?

Following governmental restrictions and taking our own precautionary measures against COVID-19 can be difficult. Students, employees, business owners, entrepreneurs, and leaders from every career and walk of life cannot escape the pervading repercussion of a more isolated environment. For those of us who are blind or visually-impaired, leaving the world that we worked so hard to adapt to, pre-COVID, gives us much more to contend with. Keeping to ourselves keeps us and others safe. Still, at the same time, it may separate us from those we depend on to assist with daily living tasks such as shopping, cooking, and cleaning.

Though we are capable individuals, work opportunities have always been restrictive. But today, it is even more limited because the pandemic has weakened our economy, causing rising unemployment across the board. Additionally, some live with a pre-existing medical condition that now cuts their eligibility for work. The risk of exposure prevents them from receiving training and working outside of their home. Those who can work now have to labor not just twice, but thrice as hard as the average employee to meet demands. We have to familiarize ourselves and cope with new work protocols. When we work from home, we don't always have the technical support we need, and accessibility often fails.

The Worst Part of Isolation

The worst part is isolation targets every one of our hearts. It prevents us from interactions that are vital to our spiritual and emotional well-being. Many are discouraged, lonely, and depressed. We are no longer allowed to physically gather with our families and friends. We postpone celebrations of milestones and life events and mourn the closing of our churches and community centers.

The good news that the disability community should embrace is this: we who experience limitations from the get-go always manage to turn disadvantages into opportunities. This is what we need to do now more than ever. We have compiled various suggestions and resources to help you be more independent and fully engaged during these turbulent times. While we are all looking forward to a time when standing too close to each other is no longer a threat, we are standing with you today to find creative ways to thrive.

NEW OPPORTUNITIES : ISOLATION OPENS THE DOOR FOR SELF-RELIANCE

We may have less contact with the people who regularly help us, but we do have the opportunity and the ability to be self-sufficient. Thanks to technology, we can rely on lifesaving tools to accomplish basic everyday tasks and more complicated endeavors like education and employment.

GROCERY SHOPPING

These are the major online membership-based grocery delivery services that hire shoppers to purchase and deliver your fresh foods and household essentials from your choice of participating local stores.

SHIPT
www.shipt.com

INSTACART
www.instacart.com

With these services, you have the ability to go through a store's catalog, pick the items you want in any amount, and check out with just a few taps. Choose when you want your delivery, in as soon as two hours.

AMAZON
www.amazon.com

AMAZON GROCERY
www.amazon.com/primeinsider/tips/amzn-fresh-news.html

PRIME DISCOUNT
www.amazon.com/prime

Grocery delivery by Amazon Fresh and Whole Foods Market is free for Amazon Prime Members. Prime membership is discounted for students and for anyone with Medicaid or EBT cards.

Many companies are eager to find new ways to serve their customers in a time when business is low due to COVID-19. Talk to your local businesses for information about available services.

TAKE OUT

We've all heard of "quarantine 15," but lockdown is the perfect time to treat yourselves to good food by "eating out" – inside! Whether you're not in the mood to cook, or you want to have a cheat day like us on Sundays, check out these accessible apps to satisfy your cravings.

UBER EATS
www.ubereats.com

DOORDASH
www.doordash.com

GRUB HUB
www.grubhub.com

SEAMLESS
www.seamless.com

MEDICATIONS

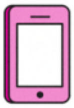
Managing prescriptions is another key to being independent. Here are five convenient strategies to getting and managing your medications.

1. To lessen the frequency of your trip to the pharmacy, ask your doctor if it's possible to adjust your prescription from a 30-day to a 90-day supply.
2. Check out pharmacy delivery options:

WALGREENS
www.walgreens.com/delivery

CVS
www.cvs.com/content/delivery/faq

3. Consider mail order pharmacy. Here is a blog post by GoodRX for info: www.goodrx.com/blog/5-things-to-consider-before-using-a-mail-order-pharmacy/
4. Use GoodRx to get prescription information, compare prices and save money. Some meds may not be covered by your insurance, and GoodRx can give you options.
5. Reading prescription labels can be a challenge and a safety concern. ScriptAbility works with select pharmacies to provide a solution by creating braille, large print, or talking labels for each medicine bottle. Talking labels are read out loud by ScripTalk app for Android or IOS or a free ScripTalk device. www.envisionamerica.com/scriptability-suite



SMARTPHONES

As a person who is blind, if I had to choose only one device to cling to, it would be my smartphone. The advent of accessibility on smartphones has irrevocably changed our lives, including the lives of people who are blind or visually impaired. With voiceover on Apple devices and Talkback for Android, it's possible to access a touch screen with no vision at all, using gestures paired with spoken feedback or using voice assistants like Siri and Google Assistant. For those who have low vision, large fonts, magnification, and color inversion are a few settings away. We can't even imagine living without our phone at our fingertips. It not only makes our lives better, it has become an indispensable accessibility tool.

BE MY EYES
www.bemyeyes.com

Connect with one of more than 4 million volunteers all over the globe to assist with challenging tasks such as reading, identifying colors, and medications, finding lost or dropped items, technical difficulties, and more through the use of a smartphone's camera.

AIRA
www.aira.io

Aira is similar to Be My Eyes, but with more capabilities and professionalism. A trained agent can read and interpret the world around you. Given permission, agents can take pictures of documents for a more hands-free experience, connect through TeamViewer to receive remote assistance on computers or smartphones, get assistance with ridesharing apps, and more.

WEZOOM
https://play.google.com/store

WeZoom is a free Android app that turns your smartphone into a digital electronic magnifier. It uses the rear facing camera on a phone, enabling those with low vision to zoom in, use color filters, freeze frame, and toggle flashlight to magnify the world around them for both near- and far-distance viewing.

The following apps use AI (artificial intelligence) to convert images on a live camera feed into spoken descriptions of objects, text, or one's surroundings.

SEEING AI
www.microsoft.com/en-us/ai/seeing-ai

Seeing AI is only available on iOS, but is a free and powerful app created by Microsoft. It uses OCR (optical character recognition) to convert physical text to an accessible format. It can also identify colors, currency, and objects using a smartphone's camera.

GOOGLE LOOKOUT
https://play.google.com/store/

Google Lookout is similar to Seeing AI and it is only available on Android. It also harnesses the power of OCR technology to make physical text accessible, as well as identifying currency, objects, and food items.

Here are other notable AI apps:

ENVISION AI
www.letsenvision.com

SUPERSENSE
https://play.google.com/store

VOICE DREAM SCANNER
www.voicedream.com

Search your app store for many other supportive apps, such as light detector, color identifier, GPS/navigation, and labelling apps.

LIVING IT UP : PERSONAL GROWTH THROUGH RELAXATION, EXERCISE, CREATIVITY AND SELF-EDUCATION

EXERCISE

Exercising relieves stress, keeps you fit and bolsters your immune system. For free accessible fitness with audio and PDF formats, work out with BlindAlive at **www.blindalive.com**

READING

Reading is always powerful. Learn about anything and everything, or escape the madness by taking refuge in a world of your choosing.

THE NATIONAL LIBRARY SERVICES FOR THE BLIND

www.loc.gov/programs/national-library-service-for-the-blind-and-print-disabled/about-this-service

The NLS for the Blind offers braille, large print, and audiobook cartridges used with a specialized player for the blind and print disabled. As a patron, you will have access to BARD online the NFB Newsline. This program grants access to local and national newspapers and magazines by phone call, iOS app or through email. Through your local library, you access Overdrive and Libby (**www.overdrive.com**), apps that allow users to borrow eBooks and audiobooks. Bookshare (**www.bookshare.com**) and Learning Ally (**www.learningally.com**) have a wide collection of DAISY books (a specialized format), including textbooks for students who are blind and visually-impaired. Members can send their books to Bookshare to be scanned and added to the collection. Audible (**www.audible.com**) is a popular vendor to purchase audiobooks. It is a paid service, but it has a wider selection with better audio quality, and new releases.

TRAINING & DEVELOPMENT

Each state provides Services for the Blind for training, technology, resources for employment opportunities, student's financial aid, and many other services.

HADLEY SCHOOL

https://hadley.edu/learn

Hadley School has a comprehensive collection of online workshops and courses for adjusting to blindness, learning Braille, technology, office programs, daily living, and independence skills. Browse their course library and learn at your own pace.

ENHANCED VISION

www.enhancedvision.com/low-vision-resources.html

Find nearby resources with this database.

FUN STUFF

Binge on your favorite shows and movies because Netflix, Prime Video, and Hulu now offer audio description, for a lot of content.

AMERICAN FOUNDATION FOR THE BLIND

www.afb.org/node/16207/games-and-activities

Check out this list of games and activities. Harness the power of your listening skill as a daring knight in A Blind Legend (**https://play.google.com/store**), an all- audio accessible app-based game.

YOUTUBE

www.youtube.com

The second largest search engine, YouTube is not only a place for music or dog and cat videos; it is a treasure trove of information about nearly anything, from learning to speak Japanese to how to fix a leaky pipe. The following are a few curated channels that can expand your accessibility toolbox. Live Accessible (**www.liveaccessible.com**): Another one of my nieces, Carrie Morales, like us, was born with aniridia. With many of her family members ranging from totally blind to low- vision, including her husband and son, she has a passion for the blind community. Through her YouTube channel, she not only shares experiences living with limited vision, but the what's and how's of assistive technology. The Blind Life: (**www.youtube.com/channel/UCNbzN3eHbLKPzltSB560DkA**) Sam Seavey has Stargardt's disease and shares tips, tricks, and how-to videos about living with a visual impairment with an emphasis on assistive technology tools "to live your best blind life." Blind on the Move: (**www.youtube.com/channel/UCPuduY__J6BEggw3wm3A2tg**) Mike Mulligan, a certified mobility instructor, shares videos on orientation and mobility (O&M) strategies, techniques, and tools. It may not replace on-site O&M classes, but with social distancing, this can be a great supplement. Life After Sight Loss: (**www.youtube.com/user/derekdanielvids**) On both YouTube and on a podcast, Derek Daniels gives hope and practical tips for dealing with emotional, social, and physical hurdles of vision loss. The Tommy Edison Experience (**www.youtube.com/channel/UCId5SIwHrXgAYRE83WJOPCw**) is an entertaining channel covering fun and interesting topics hosted by a vivacious influencer who was born blind. AMI (**www.ami.ca**) Accessible Media Inc. is a Canadian based, not-for-profit media company that also has a podcast with content that entertains and empowers the disability community.

PODCASTS

Podcasts are audio-only, deep-dive encounters for the tools, techniques, and experiences with a blindness perspective.

Blind Abilities (**www.blindabilities.com**), AppleVis (**www.applevis.com**), iSee (**www.erblearn.com**), and RNIB Tech Tips (**www.rnib.org.uk.com**) are all podcasts mostly centered on assistive technology that can enable us to be more productive. Eyes on Success (**www.eyesonsuccess.net**) and Hadley Presents (**www.hadley.edu**) cover a range of topics focused on the blind experience including motivating success stories. Blind Bargains podcast and website (**www.blindbargains.com**) shares the latest deals for the blind and visually impaired.

BLOGS & ONLINE PUBLICATIONS

If you would rather read than listen, check out these websites: Access World (**www.afb.org/aw**) is a monthly publication about assistive technology information and reviews. Blind New World by Perkins School for the Blind (**www.blindnewworld.org**) shares experiences of blind people (**#MyBlindStory**) and resources for students and parents. Cool Blind Tech (**www.coolblindtech.com**) features emerging new assistive technology and well as the market tested. VisionAware (**www.visionaware.org**) is an incredible source of information about adjusting to blindness, daily living, local services, and other life changing information for those with vision loss, and their caregivers and families. Captivating Magazine (**www.captivatingmagazine.com**) is a lifestyle magazine created by and for the disability community, covering fashion, travel, and technology.

Live It Up on Lockdown

Less time and activity out of the home shouldn't immobilize us. On the contrary, free time plus comfortable space equals ample opportunity for relaxation, exercise, entertainment, creativity, self-education and overall personal growth *(See resources, opposite page)*.

When Life Gives You Isolation, Link Up

We may have to shelter in place due to COVID-19, but we have an opportunity to break through geographical and personal boundaries by being creative in making meaningful connections. We don't have to worry as much about the expense of transportation (if we can even find a ride) to meet up with family, friends and classmates and colleagues because the whole world is now connected virtually *(See resources, below)*.

Final Thoughts

Like our relative's children, we all are waiting for a future when we can experience the world the way we used to. However, we need not allow an isolated world to make us isolated people. We hope that this EP Resource Guide will help you hold fast to the resilience that is tried and true in our unique community.•

Authors' Note: A special thank you to Carrie Morales and Guenivir Kendrick for collaborating with us on finding these resources.

ABOUT THE AUTHORS:

Jem Mabalot, born with aniridia and legally blind, is a fresh graduate of the College of Charleston with a B.A. in International Studies. Her passion is teaching the youth and learning languages such as Japanese, Korean, and Chinese. She loves exploring different cultures and wants to be a media influencer to inspire and lead the youth from different backgrounds and abilities to pursue their dream. Her calling is to establish a nonprofit organization for talent development and empowerment for children in Asia. Currently, she is teaching ESL online and working on her Certificate in Teaching English to Speakers of Other Languages (CELTA).

Christina Llanes Mabalot is physically blind from aniridia, but has a vision. She enjoys touching people's lives to bring out the best in them. "Heartsight" explains her ability to see with her heart. Christina earned her B.A. degree and Masters in Education from the University of the Philippines, Diliman, specializing in Early Intervention for the Blind. She later received Educational Leadership training through the Hilton-Perkins International Program in Massachusetts, then worked as consultant for programs for the VI Helen Keller International. She has championed Inclusive Education, Early Intervention, Capability Building and Disability Sensitivity programs. She was twice a winner in the International Speech contests of the Toastmasters International (District 75) and has been a professional inspirational and motivational speaker. Christina is blissfully married to Silver Mabalot, also physically impaired, her partner in advancing noble causes. Their children are Paulo and Jem, who has aniridia.

SOCIAL TIES : MAKING MEANINGFUL CONNECTIONS THROUGH SOCIAL MEDIA AND NETWORKS

Engaging with others will keep the loneliness and the mundane at bay, retain our sanity, give us fresh perspective, and keep us motivated even when everything else is in turmoil.

CONNECT WITH A COMMUNITY

Connect with loved ones and friends through FaceTime (**apps.apple.com**), Zoom (**zoom.us**), other calling apps, or just over the phone. For the first time in years, my extended family who lives in Canada have been able to celebrate birthdays and weddings with family and friends scattered all over the Americas by having Zoom parties. During this year, I myself have managed to become closer to all four of my siblings from all over the country and from the Philippines, just by setting regular check-in call times.

Your local church, religious or community center may have had to shut their doors physically, but bonds go beyond buildings. We can continue to encourage and serve the members of our community. Many gatherings stream or upload events. There are plenty of opportunities to meet online.

AMERICAN COUNCIL FOR THE BLIND

www.acb.org/acb-community-events

American Council for the Blind (ACB) hosts a variety of events, podcasts, presentations, and community calls daily. Engage with others about music, writing, loom knitting, employment opportunities, or just chatting over coffee, and more.

LIGHTHOUSE FOR THE BLIND

https://lighthouse-sf.org/calendar

Lighthouse for the Blind has programs, support groups, and virtual training and more.

Contact schools, camps, and centers for the blind about resources and events for children in your area.

TAPPING INTO SOCIAL NETWORKS

An increasing number of people, as we all know, are on platforms such as Facebook and Twitter. Not only can you reunite with old schoolmates and family abroad, but you can join communities of blind, visually impaired, and people of all disabilities.

FACEBOOK

Blind & Visually Impaired Support Groups

www.facebook.com/groups/259008737631118

Facebook groups are one of the most active places to connect with communities, both sighted and blind. With thousands of members, is one of the largest Facebook groups you can turn to for support and peer resources.

Whether you have macular degeneration, glaucoma, retinitis pigmentosa, or any other eye condition, search Facebook to find support and answers. There are groups for parents of blind children, assistive technology, audiobook clubs, homeschoolers, blind users of Uber and Lyft, and so much more. If the group you are looking for does not exist yet, you can create it and recruit members.

Large organizations such as the National Federation of the Blind (NFB), American Council for the Blind (ACB), and others are also on Facebook as pages or groups.Here is a list of Facebook groups to get you started: **https://liveaccessible.com/resources/facebook-groups**

TWITTER

#BlindTwitter

Twitter offers interactive conversations between large groups and individuals with every disability. Type in #BlindTwitter and you, too, can join the conversation.

Using your online discretion, the people you meet through groups and hashtags can become correspondents that can transform into meaningful friendships.

2021
EP GUIDE
NAVIGATING SPECIAL
NEEDS RESOURCES

WHAT HAS HAPPENED IN THE DENTAL WORLD DURING THE PANDEMIC – AND WHAT'S HAPPENING INSIDE OF OUR KIDS' WORLD?

BY DAVID A. TESINI, DM, MS AND LYRIC JORDAN, CLASS OF '22

THE PANDEMIC & DENTISTRY

As many of us have learned through our years, the only constant in life is change. The year 2020 has certainly epitomized life's lesson. The aspirations of a promising new year were quickly dispelled by a virus which has altered our lives and the world we once knew. Parents, children, and health care workers have been attempting to adapt to a "new normal" yet, uncertainty and anxiety still linger amongst families of children with special needs (CSHCN). The challenge of parenting has grown, it feels like the world is upside down and, in the world of children with special needs, their world has gone "wild".

A recent study that surveyed families of children with ASD found 93.9% of families reported experiencing challenges regarding managing daily activities of their children, especially more frequent and intense behavioral problems. This has also been apparent in the testimonials from families in a series called "Our COVID-19 Stories" through the American Academy of Developmental Medicine & Dentistry (AADMD). For children who rely heavily on predictability and familiarity, times of uncertainty like these can be unimaginably difficult for these children.

Through this turmoil, many are asking a very simple question. ***"What truly matters at the end of the day?"***

With the focus of family safety at the forefront of our minds, it's only natural to limit our interactions with those deemed necessary. One of the effects we have seen is apprehension towards visiting the dentist mistakenly understood to mean the risk of transmission. Dentistry has risen to the challenge – access to care, appointments available in a timely fashion, utilization of non-aerosol generating procedures such as caries arresting, visible safety precautions to in-office protocols, greater use of teledentistry, and new behavior guidance techniques. In addition, children may experience higher incidences of cavities if there is an interruption in routine dental care. It's important to continue to encourage adaptability and innovation through these times of great change. ***The "new normal" in the dental office will be driven by the experiences that parents share with the dental team***.

PREPARING FOR A "NEW NORMAL"

Eventually, this pandemic will pass and, with it, the lifestyle modifications we have become accustomed to. However, many of the new protocols in healthcare will remain. Familiarity and routine are paramount to a child's ability to feel secure in any situation,

OPEN WIDE: Dentistry has risen to the Covid-19 challenge – access to care, appointments available in a timely fashion, visible safety precautions to in-office protocols, greater use of teledentistry, and new behavior guidance techniques.

something dental offices are making a focal point when considering their special health care needs patients.

For instance, an emphasis to accommodate your child in the same dental room, with the same staff, wearing similar clothes, performing the same procedural steps, and so on. Due to the pandemic, many offices have been forced to adapt and are currently experiencing a "new normal". Check-in process may require questionnaires and temperature recordings, masks worn up until treatment is initiated, oral rinses administered when possible prior to treatments, changes in operatory designs, and extensive PPE, including gowns and face shields.

So, what does this mean for apprehensive children visiting their dentist? *Liken this scenario to visiting your local grocery store only to find everything has been rearranged. For most, it would be seen as a minor inconvenience. Yet, for those children who rely on familiarity and routine, this can become overwhelming and stressful.*

These are some of the experiences we anticipate for children coming back to the office with new protocols adopted. Anticipating this, our mission is to facilitate a smooth experience through innovative, yet readily-available means. In the American Association of Pediatric Dentistry/AAPD's "Re-entry to Practice" survey, it was reported that one of the most effective methods being used is staff wearing 6" buttons with their image so the child knows who is behind all the PPE. Tools like these help the child connect something unfamiliar to the familiar. It may also be helpful to take your child on a "virtual office tour" to explore the new changes or create updated story boards that fit the new dental office narrative. ***Collaborate with your child's dentist to create an experience that will assist them in transitioning to a new office environment.***

TELEDENTISTRY & THE IMPORTANCE FOR CSHCN

This pandemic has forced many alterations onto healthcare offices, perhaps one of the more positive has been the utilization of teledentistry. The American Dental Association (ADA) defines teledentistry as the use of "a broad variety of technologies and tactics to deliver virtual medical, health, and education services." While considered a great resource for dentists to triage patients in pain and assess dental emergencies, teledentistry has also found a home for dentists working with children who have special health care needs. Techniques like the D-Termined Program of Familiarization and Repetitive Tasking (*EP Magazine,* November 2020) have innovated to the video conference era.

Virtual visits offer a unique glimpse into the dental experience. Children can be comfortably introduced to the staff and doctors wearing new personal protective equipment like face shields. Televisits also offer dental staff the opportunity to work with children on practicing safe dental procedures such as "open mouth," "close mouth," "legs out straight" and, "hands on tummy, please." Working with the child remotely will not only save parents time by not having to drive to the office for these introductory appointments, but they will allow the child to progress in a setting they are most secure in. When the time comes to actually visit the office, it can be an exciting and rewarding experience for the child… ***and for you.***•

ABOUT THE AUTHORS:

David Tesini DMD MS ia Associate Clinical Professor Tufts University School of Dental Medicine.

Lyric Jordan is with Dentistry class'22 University of New England College of Dental Medicine.

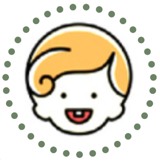
DON'T FORGET THE BASICS : FOUR CRUCIAL STEPS

Plain and simple, good oral hygiene begins at home and it begins early – soon after the primary tooth erupts. Good oral health requires discipline and parents and caregivers need only follow these four simple steps to assure a healthy smile:

STEP 1

EARLY INFANT ORAL CARE IS IMPORTANT FOR ALL CHILDREN

When that first tooth erupts, it doesn't know into whose mouth it has arrived. "Will I be kept clean?" "Will I be crowded?" it asks itself. It does not know that it has now made a home in the mouth of a child with special needs. Brushing at least twice daily, good diet (no fruit-roll-ups), no nighttime bottles or before-bed snacks, and first dental visit prior to the first birthday, are simply the first steps to a lifetime of good dental health.



STEP 2

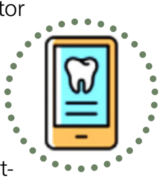
IF YOU DON'T HAVE A DENTIST YET… START LOOKING FOR A DENTIST NOW!

Ask your neighbors, friends, coworkers, pediatrician, relatives, and school contacts if they know a dentist who is able to treat your child with special needs. Remember, the capabilities of the ancillary staff–dental assistants and hygienists–are just as important as the training and experience of the dentist. Open a dialogue with the dental staff. Ask the dentist about his recommendations and experience in treating people with disabilities and how you as the parent or direct support professional (DSP) can aid in the process. Find out what you can do between visits to prepare your child to become familiar and accepting of the dental experience.

STEP 3

DO YOUR PART: KEEP YOUR APPOINTMENTS!

Many times, a breakdown occurs in the patient/doctor relationship because patients (parents/DSPs) do not take seriously the need to keep appointments and be timely. The dentist has organized her daily schedule to accommodate all her patients. You may even want to call first thing on the morning of the appointment and offer to come in a little earlier or later if the doctor would like.



STEP 4

ADVOCATE AS PART OF THE TEAM

Remember, the dentist and his staff are part of your service and support team. Accept the possibility that your own past experiences may have created some negative attitudes that will only hamper the dentist's efforts. Be open to suggestions and opinions that may vary a bit from your own. Imagine a child with a cavity whose parent says, "I don't want the fillings done because it will be too traumatic," instead of "How can we work together to get the fillings done?" Which scenario do you think is most likely to achieve a lifetime of good dental health?

– Originally published in EP Magazine, October 2001

Our COVID-19 Stories

In frequent – and sometimes frantic – conversations with colleagues, patients and friends, it was evident those with IDD experienced hardships that most outside the IDD world did not. This is how Our COVID-19 Stories was born.

BY SETH KELLER, MD

Life during the COVID-19 pandemic has been a rollercoaster – but without the excitement and thrills. We've endured the ups, downs, curves and have been tossed around. Unlike a rollercoaster, however, we can't predict what happens next. We don't know the long-term impact this year will have on us, our family, our friends, or the groups and organizations we support or who support us. Our sense of security and plans for the future were tossed out the window, and getting back to what we thought was "normal" is now our "new normal."

If you – or someone in your life – got really sick, hospitalized, or perhaps your loved one tragically died from COVID-19, then this terrible pandemic is an even heavier burden on you, as it is for my family. My mother, Mitzi, died last April from the virus. My family's very personal story is shared by over 380,000 Americans and counting. It's horrible. It's tragic. It's unbelievable. This outrageous number does not include those who had been sick and have dealt with, and even may still be dealing with the aftereffects of the virus. My family's tragedy happened early in the pandemic, and even though our mother was quarantined in her long-term care facility, it didn't matter, as she and other residents, all very vulnerable seniors, had no chance once the virus got inside the facility.

Moments before my mom passed away, my siblings and I had a FaceTime call with her to say goodbye. A FaceTime call. No soft touch, no kiss goodbye, no moment holding her hand as she slipped away. None of that. We still don't have the closure our mother and family deserve – and I'm not sure we ever will. As the virus surges across the country, we face a scary and uneasy daily life. We hope getting back to "normal" or a "new normal" is not far off. The news of the vaccination trials and their high hope of a huge reduction in the risk of further spread of the infection is a teaser. We can sort of see it, believe it to be true, hope for its safety and wish that we all can get it really quickly – but who can really be sure, judging from our rollercoaster of a year? When and where do we get off this ride?

My personal life is intertwined with my professional life. I am a neurologist specializing in the care of adults with intellectual and developmental disabilities (IDD). My practice in southern New Jersey has been greatly affected by the pandemic. We closed the office early in the pandemic and started video chats with our patients.'Aside from the person's specific neurologic difficulty, much of the conversation with them, including with their families and supports, was about the pandemic and how they were impacted one way or another. Speaking to people sitting in their kitchens, their living rooms, and even from their beds was so very personal. I got to see pictures on their walls, books on the table, the various awards that they may have won from Special Olympics. We often spoke about some of these personal items. And as we spoke about life during the pandemic, we had a deeper appreciation of the pre-pandemic life. The conversations covered what (and who) were missed, how they have adapted and tried to adjust.

It was very clear that everyone had a story to tell – and sharing them was important.

GO TELL IT: Our Covid-19 Stories believes that sharing gives others the opportunity to understand your perspective, relate to your experience and it gives them the courage to share as well.

IMAGES COURTESY OURCOVID19STORIES.ORG

The IDD Community

The unique experiences of people with Intellectual and Developmental Disabilities (IDD) often unites us as a community. We relate deeply to families caring for a loved one with a lifelong disability, the importance of family and community supports, working with experts and specialists along the way, and also feeling the need sometimes to fight the fight and advocate for the rights as a deserving citizen who has meaning and value, and to be inclusive.

As a leader in national healthcare IDD efforts, I have been involved in education, training, and policy initiatives. This work has led me to meet and work with amazing leaders in the field of IDD in the United States, as well as from across the world. I know I am not alone and when challenges arise, it is best to reach out to my friends and colleagues to learn from one another, share ideas, collaborate across disciplines of care, and advocate together. COVID-19 is no doubt a burden we must all bare together, as a community.

This is how Our COVID-19 Stories was born. In frequent – and sometimes frantic – conversations with colleagues, patients and friends, it was evident those with IDD experienced hardships that most outside the IDD world did not. How would families and Direct Support Professionals (DSP's) be impacted by the pandemic? What would happen when programs closed down, mask-wearing is mandated, social distancing and quarantining are implemented, and the concerns of a dreaded "silent enemy" remain out there and are getting worse before we get back to a new normal? What happens to the maintenance of both physical and mental health? Who is more at risk than others? Who do we look forward to so that we may receive guidance and hope for the future?

MUST-SEE: These are the stories of people with IDD and their healthcare providers during the pandemic. We must document our past for a healthy future.

ABOUT OUR COVID-19 STORIES

Our COVID-19 Stories

During this unprecedented time, the Covid-19 pandemic has changed the lives of people with intellectual and developmental disabilities (IDD) — and it is the goal of Our Covid-19 Stories to share these stories. Its mission is to document and share this unique moment in time because the lasting effects of this virus are unknown, if there are any, and how life will look post-pandemic. Covid-19 has changed daily life for everyone. For people with Intellectual & Developmental Disabilities (IDD), new normals are not easy. During this pandemic, Our Covid-19 Stories believe that it is important to capture these stories so we can remember what life was like, encourage each other and work toward a future that learns from the unique experiences of people with IDD.

We are best when we work together. We must take note of what is happening to those with IDD, their supports and families during these difficult and uncertain times. Story- telling is one of the best ways to learn, share, and to understand what others are going through. All of us in the IDD field either directly or indirectly have had a COVID-19 experience. Not all situations are tragic, nor are they totally disrupting. Resilience of the human spirit and the will to get by, survive, and make the best of a difficult situation are aspirations that we all hope to reach and achieve.

The American Academy of Developmental Medicine and Dentistry (AADMD), in partnership with Positive Exposure created an online platform – **www.OurCovid19Stories.org** – to be able to share these stories. We interviewed people with IDD, their families, caregivers, healthcare providers and DSPs. I conducted a number of these personal chats myself and have been impressed by the eagerness to share. People's COVID-19 experiences are so different, and each person has had a variety of personal and social situations related to COVID-19 at some point during the pandemic. The ups and downs are exhausting, and the desire to get to the "end" of this and to a back to normal life is an ongoing growing hope and desire we all want, sooner rather than later.

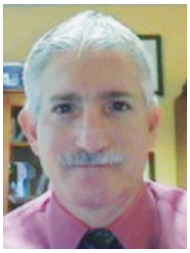
We want to get the word out to encourage more people to share their stories through this project. We're documenting the past for a healthier future. This is an opportunity to network, learn, and support each other in the IDD community. Your story might impact someone else profoundly or give others the comfort they need to tell their own story.

"Surviving" the pandemic requires us to lean on each other. All of us appreciate that the IDD world is made up of a community that includes those with IDD, their families, friends, DSP's, community support organizations, state and national leaders, as well as those healthcare providers involved in their care. We are all interconnected, and our stories need to be told together to form the whole picture.

My family's personal tragedy is part of the fabric that has been woven into this unbelievable historic period of time. Many others will also be left with memories and stories that they will never soon forget.

Please visit **www.OurCovid19Stories.org** and join this important personal campaign. Spread the word and encourage others to tell their important stories as well. •

ABOUT THE AUTHOR:



Seth M. Keller, MD is a board-certified neurologist in private practice with Neurology Associates of South Jersey. He specializes in the evaluation and care of adults with Intellectual and Developmental Disabilities (IDD) with neurologic complications. He cares for individuals with IDD both in the community, as well in New Jersey's ICF/DD centers. Dr Keller is on the Executive Board of the Arc of Burlington County as well as on the board for The Arc of New Jersey Mainstreaming Medical Care Board.

MOMENTS OF MEANING

A PHOTOGRAPHIC ESSAY BY DENNIS WILKES

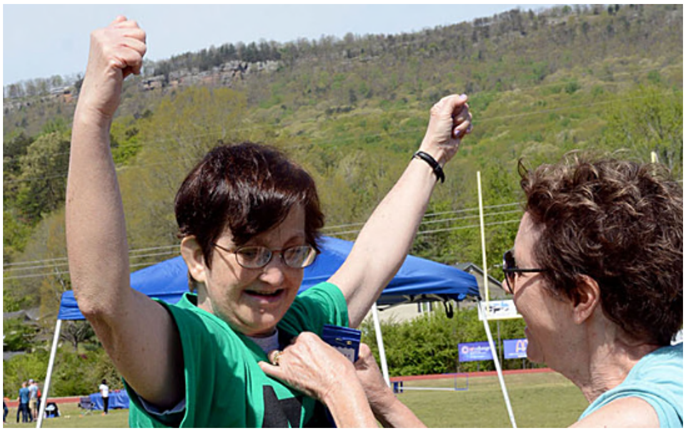
The Orange Grove Center in Chattanooga, Tennessee is a private, non-profit organization serving adults and children with intellectual and/or disabilities, one that is truly inclusive and diverse, and where all of its citizens have the skills and support necessary to live the life they want. Dennis Wilkes has been the Coordinator of the Creative Arts Program at Orange Grove for the past 44 years. At Orange Grove, art is a vital component of the services and programs that are designed to enrich and inspire meaning, as measured by such intangible but essential things as satisfaction, joy and a sense of well being.

In addition to teaching art, Dennis' responsibilities include photographic documentation of all events, production of visual graphics as needed for display, and the preparation of photos and graphic images. His talent as an artist is evidenced in the moments that he captures and shares from behind the camera, documenting examples of sport and competition, artistic expression and performance, special friendships, daily routines and even quiet reflection.

As we view these documents of unique moments, preserved with such grace and skill, we recognize the determination, exhilaration, pride, happiness and love that we all are fortunate to share in our human experience. •

ABOUT THE PHOTOGRAPHER:

Dennis Wilkes is the Coordinator of the Creative Arts Program at the Orange Grove Center in Chattanooga, Tenn. Dennis is responsible for the creation of innovative programs in art expressions for individuals with intellectual and developmental disabilities. He has been a celebrated artist, art teacher, craftsman, photographer and videographer for over 40 years. Dennis has contributed several covers to Exceptional Parent Magazine and has created many art projects at Orange Grove that illustrate the rich history of the disability.



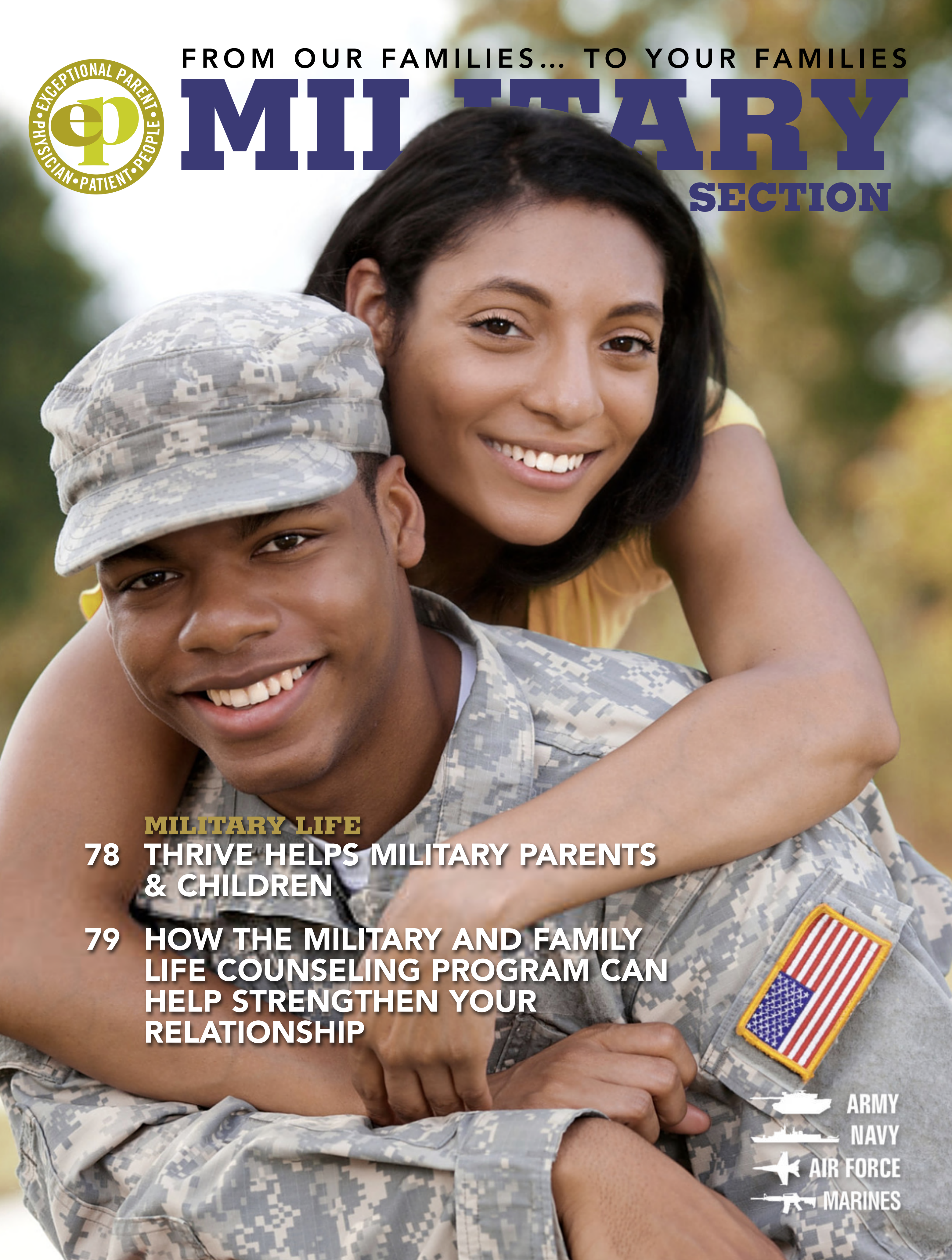
WORK OF ART: Orange Grove's art, music and Special Olympics programs are important parts of its overall mission to recognize, support, and celebrate the qualities of the individual. Music, art, and physical activity stimulate different areas of the brain and are uniquely able to bring people together. These enrichment services take place all over the community.

EXPRESS YOURSELF: While serving as outlets to Orange Grove community members, art, music and athletics improve and enhance the physical, mental, and emotional well-being of individuals with the aim of developing interpersonal skills, managing behavior, reducing stress, and increasing self-esteem and self-awareness.

EXCEPTIONAL PARENT • PHYSICIAN • PATIENT • PEOPLE

FROM OUR FAMILIES… TO YOUR FAMILIES

MILITARY SECTION



MILITARY LIFE

ARMY
NAVY
AIR FORCE
MARINES

MILITARY LIFE

THRIVE HELPS MILITARY PARENTS & CHILDREN

The Department of Defense is committed to the health and well-being of military children and families. That's why DOD teamed with the Clearinghouse for Military Family Readiness at Penn State to create a parenting-education program.

Thrive is a free online program for busy parents like you. It promotes positive parenting, stress management and healthy lifestyle practices. Find out how Thrive can help you raise healthy, resilient children from birth to 18.

HOW DOES THRIVE WORK

Thrive has four interactive modules organized by age group:

- *Take Root: for children ages 0-3*
- *Sprout: for children ages 3-5*
- *Grow: for children ages 5-10*
- *Branch Out: for children ages 10-18 (Coming in 2021)*

Each module has tips for your child's age group. Build on strengths you have and develop new skills as your child grows and changes. Suggestions include how to:

- *Find a parenting style that works for your family.*
- *Help your child make good decisions, master new skills & more.*
- *Support your child with positive discipline techniques.*
- *Model an active lifestyle.*
- *Manage stress.*
- *Be a positive role model.*
- *Communicate with your partner or support circle.*
- *Plan and prepare healthy meals.*
- *Manage screen time.*

Check out the helpful parent-resource infographics at https://thrive.psu.edu/for-parents/resources for a sample of the program.

HOW IS THRIVE DIFFERENT FROM OTHER PARENTING PROGRAMS?

Thrive grows with your child. The four age-group tracks are free, available in online formats and immediately accessible.

Other benefits of Thrive include:

- *It provides program choices that fit your family.*
- *It promotes social-emotional, cognitive and physical health.*
- *It is flexible. Pause your session at any time.*
- *It is interactive and fun.*
- *It is available to the public and shareable with family members and caregivers.*

Whether you are expecting your first baby (www.militaryonesource.mil/confidential-help/specialty-consultations/new-milparent/new-milparent-the-essentials) or raising teens, let Thrive support you along the way. Learn more and enroll in the program today. Find information about other parenting resources on Military OneSource.

Access Thrive at https://thrive.psu.edu

– Military OneSource

THRIVING TOGETHER: Thrive is a free online program that promotes positive parenting, stress management and healthy lifestyle practices.

HOW THE MILITARY AND FAMILY LIFE COUNSELING PROGRAM CAN HELP STRENGTHEN YOUR RELATIONSHIP

Military life events like deployments and permanent change of station moves can strain a relationship. But smaller issues left unaddressed can add up to big problems, too. As one Military and Family Life Counselor put it, a relationship is like a car. Both need regular maintenance to run smoothly.

MAINTENANCE ISSUES: Military life events like deployments and permanent change of station moves can strain a relationship. As one counselor put it, a relationship is like a car – both need regular maintenance to run smoothly.

Couples counseling can help you and your partner stay steady through life's challenges, big and small. In the videos below, three MFLCs provide a snapshot of relationship counseling.

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Couples counseling can help you and your partner stay steady through life's challenges, big and small. In the videos below, three MFLCs provide a snapshot of relationship counseling.

NON-MEDICAL RELATIONSHIP COUNSELING

The Military and Family Life Counseling Program and Military OneSource offer free and confidential couples counseling worldwide. MFLC and Military OneSource counselors are licensed, professionally trained and understand military life and the challenges that couples face. At many installations, MFLCs meet with couples in comfortable settings. Sessions are available by video as well. And all sessions are confidential except in suspected family maltreatment, harm to self or others and illegal activity. Learn more about MFLC at **www.militaryonesource.mil/confidential-help/non-medical-counseling/military-and-family-life-counseling/the-military-and-family-life-counseling-program/**

MORE RELATIONSHIP RESOURCES

For more insights into how couples counseling can strengthen your relationship, check out these Facebook Live events.

- *Revealing Common Relationship Challenges*
  https://www.facebook.com/7700123369/videos/770886287099204
- *Relationship Counseling: When to Reach Out, How to Get Ready*
  https://www.facebook.com/7700123369/videos/394210714963304
- *Relationship Counseling: Is It What You Think It Is?*
  https://www.facebook.com/military.1source/videos/216448283216819

Find even more resources for relationship support on the Re the We webpage on Military OneSource. View more relationship resources at **www.militaryonesource.mil/family-relationships/relationships/military-relationships-support**

CONNECT WITH AN MFLC OR MILITARY ONESOURCE RELATIONSHIP COUNSELOR

Reach out to your installation's Military and Family Support Center (**https://installations.militaryonesource.mil/?looking-for-a=program/program-service=26/focus=program**) to get started with a Military and Family Life counselor. Military OneSource also offers free, confidential non-medical counseling for couples, as well as other options, such as Building Healthy Relationships specialty consultations. Call 800-342-9647 to connect with a Military OneSource consultant or to learn more.

– Military OneSource

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E: Greetings@HighTidePress.org

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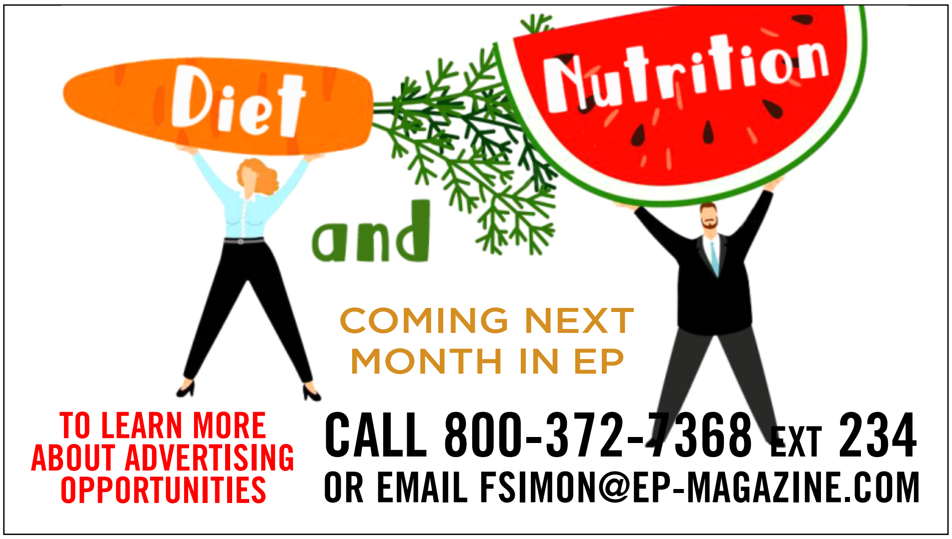

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