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MAGAZINE

AUGUST 2021
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PLUS:

DIVERGENT
BEHAVIORAL
REPERCUSSIONS
of the PANDEMIC

EP's ANNUAL ISSUE:

HEALTHCARE

INSIDE • COVID-19:

6

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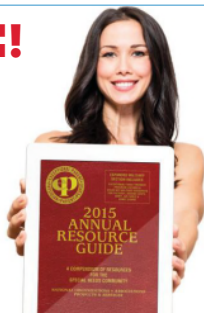
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FROM OUR FAMILIES... TO YOUR FAMILIES

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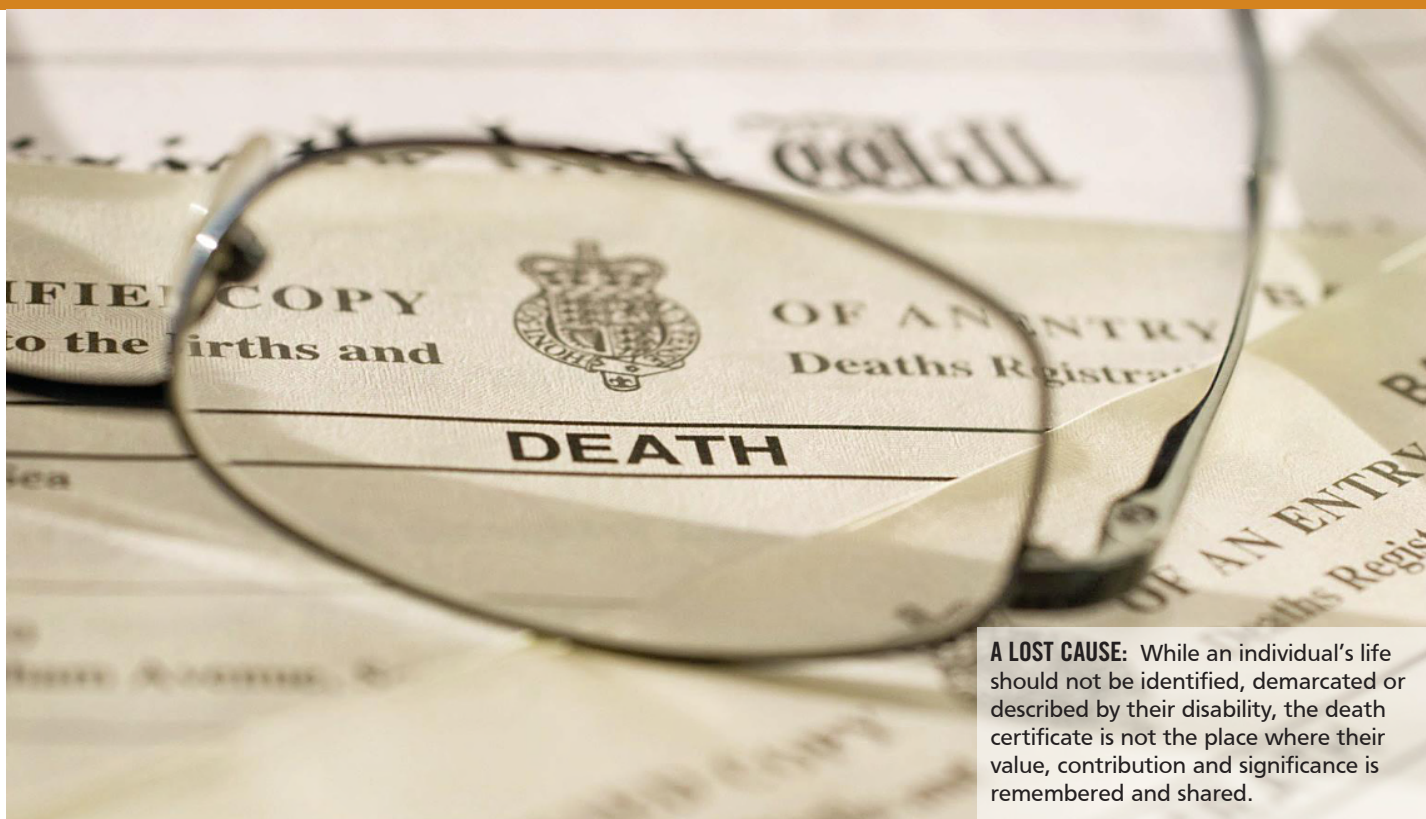
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Note from the Editor-in-chief: EP World, Inc. advocates for the dignity of all citizens with disabilities including the use of "people first language" where possible. We do not normally edit articles and submissions that do not reflect this language,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

— Rick Rader, MD

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.





Stopped Living As a Cause of Death

Beyond the “birth certificate,” and the “death certificate,” we have the “life certificate.” A timeless affidavit that describes the “cause of life” and how that individual enhanced, improved and elevated the lives he or she came into contact with.

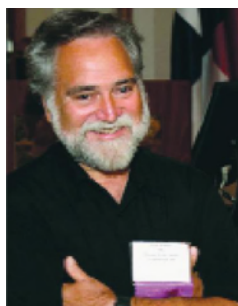
The poet Emily Dickinson remarked that *“Dying is a wild night and a new road.”*

And while that might be up for debate, neither a “wild night” nor a “new road” has ever appeared as the cause of death on a death certificate.

While it might be obvious, Sam Tetrault, writing in *The Cake Library*, makes it clear. “A death certificate is a legal document used by the state and federal government to prove someone has died.” It may be among one of the most important legal documents in our modern world, but has only become common practice when the U.S. began maintaining vital records in the early 1900s. Over time, death certificates have expanded to include more information, such as how someone died, their ethnicity, and so on. In addition, public health officials use death certificates for research and statistics. This is how they determine the leading causes of

death today and in the past. These records are valuable not only for handling someone’s legal affairs, but also for family ancestry, research, and health-care. Each state is required to comply with the U.S. Standard Death Certificate, a form issued by the Centers for Disease Control and Prevention’s National Center for Health Statistics (NCHS).

According to the National Association of Medical Examiners, the manner of death designation is an “American invention” that was added to the U.S. Standard Certificate of Death by public health officials in 1910, primarily to assist in clarifying the circumstances of death and to help those who “code and classify cause-of-death information from death certificates for statistical purpose. The options are Natural; Accident; Suicide; Homicide; and Undetermined/



Cannot be Determined.”

Historically, death records were kept by local churches along with baptism and marriage records. The Massachusetts Bay Colony in 1639 was the first American institution to have the secular courts keep these records.

In the early days of death certificates, the cause of death may have simply indicated the nature of the illness prior to death, not the exact cause of death. As medical care has evolved, we no longer see the cause of death recorded as “child bed fever,” “St. Anthony’s Fire,” “dropsy,” “vapours,” “miasmata” (foul odors from the earth), “ships fever” or “quinsy” (tonsillitis).

A review of causes of death reveal that some are described with hyper-specificity, and other times with puzzling vagueness. Take for example 951 deaths attributed to “contact

with powered lawnmowers;" 2,167 deaths due to "constipation;" over 1,800 deaths due to being "caught, crushed, jammed or pinched in or between objects;" "fall involving a bed:" 10,386 deaths; that's almost 2,000 more deaths than those from a "fall from, out of or through building or structure."

Of particular concern are the numerous errors in recording the cause and manner of death on death certificates and how they affect families, mortality statistics, and public health research.

Research studies have demonstrated that upwards of 53% had errors in accurately reporting the cause of death. There was no significant difference by the physician's specialty.

Certificates for deaths occurring in hospitals were more likely to have major errors than certificates for deaths occurring at a private residence. Clearly, the medical profession must fortify its training in the proper and appropriate use of death certificates.

Unfortunately, we still see "mental retardation" cited as the cause of death on many death certificates. It is important to capture a person's underlying disability, even if it did not directly contribute to their death. While one can debate the idea that people with disabilities die directly from their disability, or as a consequence of the disability, having that information can impact on the way we view, treat and value them. The information can be employed in research, prevention, disparities, funding and health equity.

DISABILITY STATUS IS NOT A RECOGNIZED COMPONENT OF MORTALITY DATA IN THIS COUNTRY!

The U.S. Standard Certificate of Death contains fields for a limited degree of personal information that the funeral director is responsible for filling in with information derived from an "informant" (usually a relative). These fields include age/date of birth, sex, race, length of residence in a county/state, whether someone has served in the armed forces, marital status, and

occupation at time of death, names of spouse and/or parents, level of educational attainment, and the informant's name. There is no space for recording disability status as a demographic characteristic of a deceased person. The middle "cause of death" section on the certificate must be filled out by the person who pronounces or certifies death, usually a medical examiner or coroner. This section requires an "underlying cause of death" and has room for

"conditions, if any, leading to" the primary cause of death, as well as "other significant conditions contributing to death but not resulting in the underlying cause."

"It is important to capture a person's underlying disability, even if it did not directly contribute to their death."

Because disability status as a demographic fact is not required or even asked on death certificates, it has been extremely difficult to establish even the bare fact of how many people with disabilities died from COVID-19. (Institute for Health Metrics and Evaluation, University of Washington).

And while an individual's life should not be identified, demarcated or described by their disability, the death certificate is not the place where their value, contribution and significance is remembered and shared. Beyond the "birth certificate," and the "death certificate," we have the "life certificate." A timeless affidavit that describes the "cause of life" and how that individual enhanced, improved and elevated the lives he or she came into contact with.

Maybe it's time to say "rest in peace" to death certificates that fail to portray information that may matter most. •

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



EP MAGAZINE CELEBRATES 50 YEARS AS AN INDISPENSABLE RESOURCE FOR THE DISABILITY COMMUNITY

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EP's 50th year began with the 2021 EP GUIDE to Navigating Special Needs Resources. Visit epmagazine.com/subscribe and don't miss an issue!





FROM THE PUBLISHER'S DESK

Dear Loyal Readers,

When I took over as the Publisher several years ago, my mission was to create a website where *EP Magazine* was available free to all who could benefit from the content, including archived issues. That was accomplished, thanks to the advertisers who support our magazine, because they have a product or service appropriate for our readers.

COVID-19 damaged our advertiser base and proved to be a financial challenge. I am hopeful that some of our readers would be able to help us by referring companies they are connected to, that would benefit from having a presence in our magazine and on our website.

If any of you are able to provide referrals or introductions, it would be greatly appreciated. Please send all such communications to Faye Simon, our VP of Marketing, at FSimon@epmagazine.com

Rest assured that EP will continue to provide, promote and share the best information that impacts the disability community.

Thanks for taking the time read this message and I wish you all good health and happiness.

Sincerely,

Len Harac, PhD
Publisher, *EP Magazine*

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WHAT'S HAPPENING

HOW SPECIAL OLYMPICS' FIT 5 PROGRAM MOTIVATED ME TO MAKE HEALTHIER CHOICES

As a passionate athlete, I can often be found practicing or competing at Special Olympics events or teaching others about health.

When I learned how essential good health is to doing my best on the field, it sparked a passion in me to teach others about fitness. Now, I teach fitness to audiences from my home state of Missouri – and sometimes others around the world. Special Olympics Fit 5 program includes a Fit 5 Guide and Fit 5 Cards that are designed for everyone and can be modified for any level. I tell people that it is important to listen to your body,

go at your own pace, and make sure not to overdo it. Fit 5 Cards demonstrate exercises in Levels 1 through 5 including endurance, strength, flexibility, and balance. I like Fit 5 because the exercises are customizable and are based on three simple goals: exercise 5 days per week, eat 5 total fruits and vegetables per day, and drink 5 bottles of water each day. I believe the Fit 5 program can help athletes achieve their personal best through physical activity, nutrition, and hydration.

I encourage you to check it out yourself. Today, I'm going to take you through a circuit workout with four stations that will focus on endurance, lower body strength, and balance.

FIT5 FOR FUN : SEE MORE AT www.specialolympics.org/Fit5

Station 1: Endurance

High Knees Jog in Place

1. Jog in place. Try to get your knees as high as you can with each step.
2. Swing your arms the whole time.



Featuring Special Olympics Global Messenger, Bryce Cole

Station 2: Strength

Side to Side Hops

1. Bend the knees slightly and hop as high as you can to one side then the other side.

NOTE: You can also hop forward to backward or hop in place.



Featuring Special Olympics athlete leader, Novie Craven

Station 3: Endurance

Frog Jumps

1. Start by standing with your feet apart.
2. Bend at your knees and hips to squat down. Touch the floor with your hands.
3. Jump straight up in the air with your arms up.
4. Land in a squat with your hands touching the floor.



Featuring Special Olympics athlete, Danilo Benitez

Station 4: Strength

Chair Squats

You will need a chair for this exercise. You may want to put the chair next to the wall for safety.

1. Stand in front of the chair with your arms straight out in front of you. Your feet should be as wide as your shoulders.
2. Bend your knees and hips. Lower yourself until you are seated in the chair. Do not use your hands.
3. Now stand up. Try your best to only use your legs (not your arms).



Featuring Special Olympics CEO, Mary Davis

Station 5: Balance

One Leg Deadlift

1. Start by standing tall with your feet together. Put your arms out to your sides at shoulder height.
2. Balance on your right foot.
3. Keep your left leg straight. Slowly lean forward and lift your left leg behind you.
4. Slowly stand up without touching your left foot on the floor.
5. Do all repetitions on one side and then switch to the other



Featuring Special Olympics athlete, Matthew Whiteside

Perfect Portions



Here is a fun way to remember how much to eat when you have a serving. The size of sports equipment on the left is about the same size as one serving of the foods on the right.



baseball



1 serving of fruit



1 serving of rice or pasta



1 serving of vegetables



hockey puck



1 serving of bread



1 serving of beans



1 serving of meat



golf ball



1 serving of cheese



1 serving of nuts



1 serving of nut butter

After a tough workout it's important to fuel your body with the proper nutrition. Fit 5 highlights the importance of what we put into our bodies. I wanted to share a fun way to remember how much to eat when you have a serving. The size of the sports equipment on the left is about the same size as one serving of the foods on the right. Remember, moderation is key to anything, so we can enjoy a yummy treat every now and then if we do so in moderation.

WHAT'S HAPPENING

TRIAL OF DCA IN PDC DEFICIENCY

The University of Florida is sponsoring a clinical trial to determine if treatment with an investigational drug called dichloroacetate (DCA) can improve the health and function of children diagnosed with PDCD.

Pyruvate dehydrogenase complex deficiency is the most common cause of congenital lactic acidosis and is frequently a fatal metabolic disease in childhood for which there is currently no proven treatment. DCA has been designated as an Orphan Product for the treatment of congenital lactic acidosis by the Food and Drug Administration (FDA).

It is important to be able to find a treatment for PDCD due to its rare disease status and the fact that the life expectancy of most affected children is severely shortened. Additionally, PDCD is an extremely debilitating disorder that causes neurologic impairment and developmental delays in affected patients. In order to determine if DCA works to improve the health and function of children with PDCD, completion of enrollment into the clinical trial is

extremely imperative, as it will allow the ability to evaluate the effect DCA has on PDCD patients, in the hopes that it will be effective and will possibly be approved by the FDA as an official treatment for PDCD. As this is a rare disease, there are only so many patients available with PDCD to participate in the trial. It is important to expand awareness of this trial to ensure enrollment into the study can be achieved.

Approval of DCA as an official treatment for PDCD would likely reduce the economic burden on families associated with frequent hospitalizations and home management of a chronic illness.

The study is being conducted at nine academic centers across the United States. To locate a center near you, please click on the link below to the study listing on ClinicalTrials.gov. Travel assistance is being provided if needed.

ClinicalTrials.gov link: [Trial of DCA in Pyruvate Dehydrogenase Complex Deficiency](#)

For more information about the clinical trial, please contact Peter W. Stacpoole, PhD, MD, Professor of Medicine, Biochemistry and Molecular Biology at the University of Florida College of Medicine via the phone or e-mail: pws@ufl.edu ; Phone: 352-273-9599. •

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Individuals with Disabilities as Effective Healthcare Workers

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

In a few short years, your teenager with a disability will be completing her/his high school education. What's next? A college education, an entry level job opportunity or just thinking and hoping for some eventual job?

*"People with disabilities can pursue successful careers in the healthcare field, but it's not easy. The opportunities are out there, and so are the obstacles, from facilities and equipment that may need expensive accommodations to licensing requirements that necessarily put patient care and safety above all else. It's often the organizations and resources job seekers with disabilities use that make all the difference when it comes to landing a healthcare job."*¹

Probably the most difficult questions to be considered for a soon-to-be young adult child (and for the teenager with a disability) would be regarding the type of employment: 1) Am I capable of handling such a job? 2) Will I be faced with discrimination because my disability? Every job seeker knows the importance of determining if a position is a good fit. For workers with disabilities, however, that knowledge is even more crucial. Working in an ill-fitting environment is more than emotionally taxing; it can be physically harrowing.

There is also the reality that many teenagers change their mind regarding career paths. For example, one of the authors (HBW) was an 18-year-old, first-year dental student in 1954, when the dean of school asked him whether he would consider a career as a dental school instructor. The emphatic response was NEVER! In 1963, this older (and wiser?) practitioner began his still-ongoing 57th year of clinical and didactic university dental school teaching.

Your child and you should carry out an extended effort to review potential areas of interest for employment before your teenager settles on a specific career. The Bureau of Labor Statistics' Occupational Outlook Handbook describes different pro-

fessions' tasks, working conditions, training and education required, earnings and expected job prospects. The Job Accommodation Network also offers extensive services.²

Once the youngster narrows the choices, remember to keep researching. A lot depends on the workplace environment. For example, large corporations with multiple locations might allow more flexibility; is telecommunication a possibility?

HOW ABOUT A CAREER PATH AS A HEALTHCARE WORKER?

*"Healthcare occupations span the gamut in terms of tasks, educational and performance requirements. Although it might be difficult to become a paramedic or EMT with some kinds of disabilities, other occupations such as dietetics or health information could offer opportunities. Medical transcription is another possibility for a healthcare career. Dispensing opticians, optometrists, pharmacists and speech-language pathologists could be disabled and still perform the essential functions of their jobs. Medical billing and coding are another option for a person with a disability who has physical limitations. A disability need not limit your chances to work in healthcare."*³

Keep in mind, after growing up with a disability, she/he must have had uncountable numbers of first-hand experiences and probably has become an expert on the receiving end of health care services from a wide range of providers. While receiving and providing care are opposite ends of the "system," your former teenager has had ample opportunities to experience and observe the many advantageous and unfavorable components of healthcare worker's activities and the difficulties to be faced by the worker and the patient.

People with disabilities can pursue successful careers in the healthcare field, but it's not easy. The opportunities are out there, and so are the obstacles, from facilities and equipment that may



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.

need expensive accommodations to licensing requirements that necessarily put patient care and safety above all else. If only because they must comply with the Americans with Disabilities Act, major healthcare employers – from home-care agencies to hospitals – are finding ways to integrate workers with disabilities into their workforces.¹

A first step would be to contact The Society of Healthcare Professionals with Disabilities which can provide resources and support for medical professionals, physicians, nurses, pharmacists, therapists, clinicians, and students with disabilities.⁴ Learn the educational, license requirements, preparation for employment, probability of employment and salary potential. Ultimately, a decision is made and the young adult will have completed the required preparatory steps to seek employment.

GETTING THE JOB

The reality is that people with disabilities may have to work harder to secure a new position. The most important job search tool – the resume – has to be thorough and well done.

Should you disclose a disability on your resume? “The first thing job seekers need to ask themselves is, ‘Can I do the job?’ If the answer is yes and the disability doesn’t affect job performance, then don’t mention it... Never reveal a disability on a resume... citing the possibility of discrimination or preconceived, inaccurate notions about disabilities...”⁵

KNOW YOUR RIGHTS

There are federal laws that protect job seekers with disabilities. The Americans with Disabilities Act (ADA) of 1990 makes it illegal for employers to ask job candidates about their medical history during a job interview. More important, it requires employers to provide “reasonable accommodations” to qualified job applicants or employees.

A reasonable accommodation is any modification or adjustment to a job or work environment that will enable an employee with a disability to perform essential job functions. (Reasonable accommodation examples include modifying the height of desks and equipment, installing computer screen magnifiers, or installing telecommunications for the deaf.)



SORTING IT OUT: Healthcare occupations span the gamut in terms of tasks and requirements. Dispensing opticians, optometrists, pharmacists and speech-language pathologists could be disabled and still perform the essential functions of their jobs.

Notes: “It is illegal for employers to ask questions about a disability until a job is offered... You cannot get accommodations without disclosing your disability before accepting a job offer... There is no shame about requesting an accommodation you need in order to be successful at your job.”⁶

The Job Accommodation Network (JAN) is a service provided by the U.S. Office of Disability Employment Policy. JAN facilitates the employment and retention of workers with disabilities by providing employers, employment providers, people with disabilities, their family members, and other interested parties with information on job accommodations, entrepreneurship, and related subjects. JAN’s efforts are in support of the employment, including self-employment and small business ownership, of people with disabilities.

ASSUMING EMPLOYMENT IN THE HEALTHCARE FIELD DIDN’T WORK OUT

The time, effort, expenses and emotional expenditures have not been wasted. Instead, the challenges can better prepare the young woman or man with disabilities for a second (or more) try. The lessons learned from applications, interviews and more can be an essential learning process for a youngster’s initial introduction to the realities of hiring individuals, with and without disabilities.

PARENTAL GUIDANCE

Fifteen to 20 or more years of support for your developing child with a disability (and the entire family) have taught you that seemingly insurmountable obstacles can and will be overcome. The need is now to continue to transmit this determination to your special child.

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EMBARKING ON A COMPREHENSIVE FINANCIAL PLANNING PROCESS

BY PAT BERGMAIER, CFP®, CHSNC™

The primary goal of most parents, my wife and I included, is to provide for our children when they depend on us. There is an added challenge when a child has a disability, as this dependence may never end. It is important for families who have this type of planning situation to embark on a comprehensive financial planning process that incorporates the needs of all family members – the parents, their child with a disability, and their other children/heirs.



While there is no cookie-cutter approach to this type of planning, families need to take these necessary steps:

1. Look to maximize government benefits.

There are very strict eligibility rules to receive government benefits. For example, to receive SSI and Medicaid, an individual cannot own more than \$2,000 in his/her name. Navigating government benefits can be an intimidating and, often-times, a frustrating part of a special needs plan, but the goal is to not leave anything on the table.

Key Planning Point: Remember, these benefits typically provide a floor of supports for your loved one and may not provide the life you would want for them when you are gone!

2. Use the right attorney! Estate planning generally involves the drafting of wills, medical and financial powers of attor-



ney, and sometimes trusts. The planning becomes more complicated when it involves a loved one with special needs and therefore requires a higher level of expertise. That is why it is important to work with the right attorney, one who has the knowledge and experience in drafting a Special Needs Trust. The goal of a properly drafted Special Needs Trust is to maintain eligibility for certain government benefits while providing quality of life and lifetime care for a loved one with special needs. Also, the attorney should have experience with counseling parents on the advantages and disadvantages of either pursuing guardianship or having your loved one sign a power of attorney once he or she turns age of majority – usually at age 18.

Key Planning Point: *Special needs planning does not begin and end with simply having your legal documents in place. A Special Needs Trust document is different than a Special Needs Trust fund. You need to coordinate your financial and tax planning to make sure your trust gets funded!*

3. Financial planning for two generations. Planning for what I've referred to as a "3-person retirement" shifts the focus on how we need to plan. All investment, insurance, tax and other financial planning decisions should focus on these two outcomes/goals. Ask yourself the question: "Will this financial decision provide me more income in retirement and also be an effective strategy for funding my loved one's future when I die?" Our top two priorities for all of our clients are:

- Maximize the caregivers' quality of life – Think about when the flight attendant on the plane says "Parents, please put your oxygen masks on first before you help your children." Your "oxygen mask" translates to being able to retire at the highest amount of sustainable income for the rest of your life. More income for you allows you the flexibility to continue to support your disabled adult child through your retirement but also help other family members.
- Fund the special needs trust – Let me elaborate: adequately fund, in the most cost-effective and tax-efficient manner possible, your loved one's special needs trust to provide for their lifetime care and quality of life, in the way YOU want this to happen.

Key Planning Point: *Parents, you are the living, breathing "special needs trust" while you are alive. Today, if your child needs for something, who pays for it? In retirement, when your child needs something, who will pay for it then? In most cases, the need for the funding of a special needs trust to occur hopefully isn't for many, many years down the road!*

4. Consider the ongoing care management of the child. Parents generally are the primary caregivers of their child with special needs. But who will care for their loved one when they are gone? It is important for parents to create a plan that addresses everything they do for their loved one daily. Parents should create a document called a Memorandum of Intent to provide information that caregivers might need to know about their son or daughter and their wishes for ongoing care as well as. A caregiver may be a family member of other individual, or it may be an organization that provides care management services as a complement to services received through government programs.

Key Planning Point: *Transition planning is a common phrase in a special needs parent's life. You plan for transitioning your child from early intervention into school, then deal with your first of many Individualized Education Programs (IEPs). Then you start the seven-year transition plan at age 14, until transitioning out of school at 21 and are now also dealing with Individual Service Plans (ISPs). What is the third transition then? From living with a parent to living elsewhere in the community. A plan for this transition needs to be discussed, as hard as it might be, as this will have a tremendous impact on the quality of life for your loved one!*

The process of creating a comprehensive financial plan requires working with a qualified financial professional. Financial professionals not versed in special needs planning will often advise all their clients the same when it comes to their investment, insurance and retirement planning. You cannot be put into a box when you have a loved one who is going to rely on you for the rest of his or her life. You should look to partner with your advisor and build a plan unique to both your future needs and your loved one's future needs.

Don't settle for "OK" when it comes to your finances. You haven't settled for an "OK" IEP from the school district, right? You probably wouldn't have been satisfied with an "OK" therapy plan from your medical professionals. Too frequently, families don't take the time to address their financial planning appropriately because they are "OK" in that regard. Common financial and estate planning missteps go undetected if experts are not used, resulting in inefficiencies and sub-optimal plans.

Financial planning for families with special needs requires looking at everything from a very different vantage point. If done right, though, it can make a real difference in not only your loved one's quality of life but the quality of life of other family members as well.

Where to seek answers? In addition to national organizations devoted to special needs planning, seek a locally- recommended Chartered Special Needs Consultant (The American College of Financial Services), or a CPA and/or financial planner specializing in planning for those with special needs to see how a medically related capital expenditure may reduce your tax bill. •

[Author's Note: This article is for informational purposes only and should not be considered as specific financial, legal or tax advice. Depending on your individual circumstances, the strategies discussed in this presentation may not be appropriate for your situation. Always consult your legal or tax professionals for specific information regarding your individual situation.]

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Pat Bergmaier, CFP®, ChSNC™, now in his 17th year as a financial advisor, has focused his practice since 2009 on special needs financial planning. Pat has obtained his CERTIFIED FINANCIAL PLANNER™ (CFP®) certification through the CFP® Board and the designation of a Chartered Special Needs Consultant™ (ChSNC™) through the American College of Financial Services. Pat and his team support many local special needs non-profit organizations in the Philadelphia area; and he also serves on the advisory board of the Mass Mutual Center for Special Needs at the American College of Financial Services.



2021 Advance Child Tax Credit Payments

Payments start July 15

Filed already?

You don't need to take any action now if you've filed a 2020 tax return.

Haven't filed yet?

File your tax return as soon as possible. For people not required to file a tax return and who didn't file in 2019 or 2020, quickly register using the **IRS Non-filer Sign-up Tool**. You may qualify for the Child Tax Credit and Economic Impact Payments.

- Eligible families can receive advance payments of **up to \$300 per month** for each child under age 6 and **up to \$250 per month** for each child age 6 and above.
- Payments begin July 15 and will be sent monthly through December 15 without any further action required.
- You can benefit from the credit even if you don't have earned income or don't owe any income taxes.
- The tax credit includes advance payments for 2021 only.

The American Rescue Plan Act Advance Child Tax Credit provisions include:

- The maximum Child Tax Credit increased to \$3,600 for children under the age of 6 and to \$3,000 per child for children between ages 6 and 17.
- The credit includes children who turn age 17 in 2021.
- Taxpayers may receive part of their credit in 2021 before filing their 2021 tax return.

Eligible taxpayers who don't want to receive advance payment of the 2021 Child Tax Credit will have the opportunity to unenroll from receiving the payments.

[IRS.gov/childtaxcredit2021](https://www.irs.gov/childtaxcredit2021)



LIFE INSURANCE BASICS

BY ROB WRUBEL, CFP®

When I was younger, I loved reading the stories of the Greek gods. The gods had a majesty to them. They could go anywhere, change shape and wield great power. And, they were immortal. Of course I could dream of immortality, even as I understood it was not possible for me.

Every day there's a news story about a person who died unexpectedly. In Colorado, where I live, there was a story this June about a person dying from a skiing accident. There are no shortages of people passing away from car crashes, unforeseen health crises, or other accidents.

As a financial planner, we talk about life expectancy in my work. We have to make some assumptions about how long we will live so that we can take action to save and invest today, to be able enjoy life and have funds to pay for expenses for our entire lives. For families with members who have special needs, we also plan for the second generation and seek to devise strategies to fund trusts to pay for future needs – and have these funds available, whether we live long lives or leave this earth earlier than expected.

Life insurance provides cash for your family members. It can be a useful tool in special needs planning. Unfortunately, I see too many instances of people using life insurance in ways that do not fit their financial lives – they buy too little coverage for too much money with policies that try to do too much.

Let me give you some tips.

- 1. Buy the right amount of death benefit.** Life insurance covers lost income and a lack of savings. Funds paid out can be used to pay off or pre-pay expenses, like funding a trust or college. The most important piece, in my opinion, is to cover lost wages. There's a basic rule of thumb saying you need seven to 10 times your income in benefit. That is a good starting place, but work with your agent to fine tune it to your needs.
- 2. Start with term insurance.** 20-year or 30-year term is usually the right type of coverage for most people, especially those getting started building income and assets. You get the most bang for the buck with term insurance – the lowest premiums for the most coverage.
- 3. Review your coverage, at least every 10 years.** If you save, invest, pay off debt and build wealth; you will need less coverage over time, not more. For some, they will need coverage to last longer and buy an extra policy as time goes by, especially if they didn't focus on building wealth. You can ladder policies to meet needs. I have several clients with staggered policies to meet specific needs.



4. Don't mix investing and insurance. This is true most of the time. Certain policies have cash values that have the potential to earn a return. In my practice, I've seen that those who sock away funds into retirement and investment accounts save more than they do inside their life policies with cash values.

5. Update beneficiary designations. In special needs planning, we don't want to leave money to our family members with intellectual and developmental disabilities. Their share of the estate typically goes to a special needs trust. Review your policies to ensure you've made the necessary changes.

Financial planning requires us to look at difficult aspects of life, like our own mortality. We can dream of living an eternity and of outliving our family member with a disability. We cannot guarantee it. In my book, "Protect Your Family," I give more thoughts on how to think about insurance. Whatever you do, put a strategy in place to provide financial support for your loved ones. •

ABOUT THE AUTHOR:



Rob Wrubel is a CFP who has a daughter with Down syndrome. He is recognized as a leading expert on financial planning for families with special needs members. Wrubel has written two books about financial planning and special needs families – *Financial Freedom for Special Needs Families: 9 Building Blocks to Reduce Stress, Preserve Benefits, Create a Fulfilling Future* and *Protect Your Family: Life Insurance Basics For Special Needs Planning* – and he has been published recently by Law360.com and The Good Men Project. Wrubel holds the Certified Financial Planning (CFP®) designation, the Accredited Investment Fiduciary® (AIF®) designation from F360, and the Accredited Estate Planner (AEP®) designation from the National Estate Planning Council.



annual
HEALTHCARE
issue



WHY THE IMPACT OF COVID-19 ON PEOPLE WITH IDD IS SO DEVASTATING

BY DAVID A ERVIN, BSC, MA, FAAIDD

Soon after the COVID-19 pandemic established a foothold in the US, evidence quickly pointed to its debilitating impact on people with intellectual and developmental disabilities (IDD). While most media coverage spoke to the virus' impact on older people and people living in nursing homes, very little attention was being paid to the community of people with IDD and its experience of COVID-19. Nonetheless, as a New York Times article would reveal, people with IDD were dying from COVID-19 at a rate far greater than their peers without IDD.

*“People with IDD have been impacted by COVID-19 unlike any other community. Yes, we can be this unequivocal. Study after study tells a grim tale. Paraphrasing a commentary in the New England Journal of Medicine Catalyst entitled *The Devastating Impact of COVID-19 on Individuals with Intellectual Disabilities in the United States* (Gleason, et al., 2021), people with intellectual disabilities experience higher incidence of COVID-19 infection, higher rates of hospitalization and need for ICU, and higher rates of death due to COVID-19 infection than virtually any other cohort.*

The commentary is appropriately titled – devastating impact. Research from 11 states and the District of Columbia show that fatalities from COVID-19 among people with IDD are as much as 8.6 times higher than death from the virus among people without IDD (Landes, Turk & Ervin, 2021). In another study, Landes and colleagues (2021) demonstrate disproportionately high COVID-19 case rate, case-fatality rate, and mortality rate among people with IDD being supported in New York City residential settings.

As people with IDD, their families and friends, and support providers reacted to these realities, we all began to wonder why. Why were people with IDD so disproportionately impacted by COVID-19? Surely, the mere presence of an IDD wasn't the issue – it had to be more than that. But, what?

As early in the pandemic as July 2020, Turk, et al. (2020) published analyses of a large sample of people with IDD who contracted COVID-19. This study suggested that people with IDD have higher prevalence of comorbid risk factors (i.e., hypertension, heart disease, respiratory disease, and diabetes) often associated with poorer COVID-19 outcomes, including death. Many of us had, even then, come to understand the common conditions that, when combined with COVID-19, resulted in terrible outcomes. The Centers for Disease Control and Prevention (CDC) had issued alerts as to these conditions, including obesity, pulmonary disease and other forms of inflammation. As it happens, these are conditions that are quite common among people with IDD. In fact, these and other co-occurring, chronic health conditions, otherwise known as co-morbidities, are experienced by people with IDD at rates that are generally higher than by people without IDD. This reality has been long established in the scientific literature and long before the COVID-19 pandemic.

We also came to quickly understand the impact of the settings in which people with IDD live on the likelihood of contracting and experiencing severe outcomes from COVID-19. Put simply, people living in congregate environments – group homes, intermediate care facilities (ICFs) and skilled nursing facilities (SNFs), for example – were contracting the virus at rates that were higher than people with IDD who were living in their own homes or with their families. Especially stark is data from ICFs and SNFs in California, which shows a death rate among individuals with IDD that is as much as 8.6 times the general death rate of all Californians from COVID-19 (Landes, Turk & Ervin, 2021). These and other data like them pointed to congregate settings as a risk factor for contract-

ing and experiencing poorer outcomes from the virus.

It's worth repeating that the presence of an IDD on its own appears to have no relationship to rates of contracting or outcomes experienced from COVID-19. As outlined above, pre-existing conditions that people with IDD experience at higher rates of prevalence, and where and how a person lives are critical factors. Now that we know these are the things that have really mattered

through the pandemic, we're left to ponder what it all means for us going forward. In other words, so what?

We'd be forgiven for believing that a one-in-a-hundred-years pandemic can't possibly happen again. We'd be forgiven for our want to resume our lives and the way we think about the world around us like we've always done. We are anxious to put this all behind us. But there are essential lessons the pandemic teaches us.

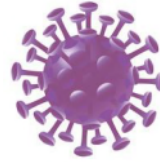
SITUATION IS WORSE WHEN COMBINED WITH COVID-19

People with IDD experience poorer health status and poorer access to culturally competent and accessible primary and specialty health, behavioral health and dental care. We have known these things for decades, and they are primary drivers of the co-morbidities—easily

treatable conditions, by the way—that, when combined with COVID-19, have resulted in such terrible outcomes for people with IDD. There are many reasons, all well enough documented, for these realities. Readers of *Exceptional Parent Magazine* will be all too familiar with them.

- **People with IDD rely on Medicaid as their health insurance in huge numbers.** Because Medicaid rates of reimbursement are poor, finding a provider to care for people with IDD is difficult. When care is available, it is often characterized by quick, infrequent encounters that preclude fully-informed diagnoses, review of treatment options, or a full understanding of social determinants of health. Adults with IDD particularly are rarely (and, we mean rarely!) covered by private health insurance.
- **Healthcare providers are not being trained or prepared for providing care to people with IDD.** There is no recognized specialty in developmental medicine (the adult equivalent to developmental or neurodevelopmental pediatrics), no board certification, and no medical school curriculum built particularly around adults with IDD. While a growing number of medical schools include exposure and some didactic, experiential care components that include adults with IDD, it remains a rarity.

“Research suggests that pre-existing conditions people with IDD experience at higher rates of prevalence, and where and how a person lives are critical factors. Now that we know these are the things that have really mattered through the pandemic, we’re left to ponder what it all means for us.”



- **Health promotion and wellness care designed with, by, and for people with IDD, is hard to find and harder still to access.** From physical activity and exercise resources to tobacco cessation materials, from heart healthy nutrition to weight loss programs – all essentially ubiquitous in communities of people without IDD – there is little to no accessible resources designed for communities of people with IDD.

Beyond healthcare resources accessible to people with IDD before the pandemic, the exclusion of people with IDD and the families, friends and professionals who support them has persisted during the pandemic. An April 2020 survey of nurses who identify as specialists in nursing for people with IDD showed a “startling absence of public health guidelines for people with IDD and an equally startling exclusion of nurses specializing in IDD from pandemic response and planning” (Desroches, et al., 2021). There were so many occasions of people with IDD sick with COVID-19 being denied access to the full array of medical care and hospital services that the US Department of Health and Human Services Office for Civil Rights issued a bulletin stating that “persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person’s relative ‘worth’ based on the presence or absence of disabilities or age” (United States Department of Health and Human Services Office for Civil Rights, 2020).

Sabatello and colleagues (2020) put it this way: “With people with disabilities entering the COVID-19 pandemic worse off than their non-disabled peers in terms of risk factors for more severe outcomes, a broken healthcare system with a history of medical biases against people with disabilities, and an absence of consolidated disability-friendly guidelines for emergency preparedness, it is likely that people with disabilities are discounted, and as result, fairing comparatively worse than their non-disabled peers in the community”

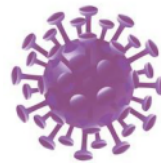
HIGH RISK OF INFECTION IN CONGREGATE SETTINGS

We have also learned, during the course of the COVID-19 pandemic, that congregate settings are directly correlated with higher rates of infection and severe out-

comes. As seemingly ever, though, the issues that define the relationship between the type of residential environment in which a person lives and their experience of COVID-19 are complex. In the early days of the pandemic, as it became clear that people in group living environments were more likely to be greater risk for COVID-19 infection and severe outcomes, there was a modest push to discontinue any congregate settings. While there’s a worthy debate over the wisdom of these residential options, there are larger issues that must be considered.

We know, for example, that people with IDD who are receiving formal, govern-

“We all need to demonstrate our ability to making lasting change to systems of care and support that quite simply have failed people with IDD through the pandemic.”



ment-funded supports tend to need and want more intensive supports. Many people living in ICFs and SNFs have complex health conditions and support needs that make them substantially more vulnerable to COVID-19. That people with IDD in these settings experienced a case fatality rate more than four times (4x) the general population is not surprising, and is less likely to do with the setting in which they live and more to do with their complex health needs and proximal nature of their care.

With that said, there is little debate that in congregate settings, where social distancing is not always possible – and in which a greater number of unrelated people are living in close proximity, supported by direct support professionals (DSP) who are typically coming and going on a rotating shift-based staff model – risks of infection with COVID-19 have been, and remain higher than in more individualized residential options. Landes, et al. (2021) note that the number of people living in a residential setting is an important consideration, and that people with IDD living in

group environments necessarily interact with their housemates and the staff who support them. The higher the number, the greater the frequency and proximity of interaction, and the greater the risk of contracting the virus. While this doesn’t make all group homes and other congregate living models bad, it does offer important lessons to which we must pay close attention.

LOOK TO MAKE LASTING CHANGE TO SYSTEMS OF CARE AND SUPPORT

All of this must inform critical steps forward in public policy and, more generally, the ways we contemplate the quality of lives of people with IDD. There are things that we can and must do – from self-advocates to providers and practitioners, from friends and family to colleagues and co-workers. We all need to demonstrate both our ability to learn from the COVID-19 pandemic and our resolute commitment to making lasting change to systems of care and support that quite simply have failed people with IDD through the pandemic.

1. As Constantino, et al. (2020) point out, there are few groups who are at greater risk for COVID-19 infection than people with IDD. The co-morbidities that combine with COVID-19 to result in severe outcomes are easily prevented. However, they are co-morbidities that need routine care through culturally competent and accessible healthcare. The American Academy of Developmental Medicine and Dentistry (AADMD) estimate Medicaid savings of as much as \$7 billion if healthcare providers were appropriately trained to the health needs of people with IDD (www.aadmd.org/ncidm). Over the past 15 years, primary and specialty healthcare delivery systems, designed with and for people with IDD, have demonstrated efficacy, both in terms of improvement in health and cost savings (see Ervin, et al., 2014; Wilson, et al., 2020). Several projects deserve our attention, including the Westchester Institute for Human Development Medical Home (www.wihd.org/programs-services/adult-health-services) in New York, the Lee Specialty Clinic (www.leespecialtyclinic.com) in Kentucky, and the Developmental Disabilities Health Center (www.peakvista.org/location/developmental-disabili-

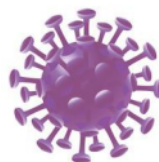
ties-health-center-colorado-springs-co-80917) in Colorado. There are others, all of which offer models that can and must be replicated at some scale if we are to meaningfully address the lifelong health needs of people with IDD.

2. Most healthcare practitioners have had no formal training or experience with people – adults particularly – with IDD during their formal education and training. The Alliance for Disability in Health Care Education (www.adhce.org) is a not-for-profit organization of medical school faculty, nursing school faculty, and other healthcare educators who are working to integrate disability-related content and experiences into healthcare training programs. Their Core Competencies on Disability for Health Care Education (Alliance for Disability in Health Care Education, 2019) provide a useful framework in developing healthcare providers who are in training. In addition, the National Curriculum Initiative in Developmental Medicine (www.aadmd.org/ncidm) offers a medical school curriculum framework to teach learners how to improve their clinical skills when treating patients who live with an IDD (Holder, 2016). These resources must continue to be utilized widely to support efforts to educate current and future healthcare practitioners, in order to improve access to culturally-competent primary and specialty healthcare.

3. The debate over congregate living will continue. Many families that include a member with an IDD, faced with impending high school graduations and the uncertain future that tends to follow, must contemplate how, where and with whom that member will live. Is there a group home provider that is trustworthy? Is a host home (also called shared living in some places) a better model, where the person with the IDD lives not with their own family, but with a host home provider and, potentially, their family? Can and does the person want to live alone? Do they need less intensive supports in order to achieve what they seek to achieve? Or, is it preferred that the person with the IDD continue to live at home, even after they turn 21?

These and countless other questions like them frame the frequently challenging process of determining, ultimately, where and with how many people the person with the IDD will ultimately live. There is no doubt that people living in group homes, ICFs and SNFs fared worse than their peers who lived alone or with families (Landes, Turk & Ervin, 2021). More than 681,000 adults with IDD living in congregate living environments, owing primarily to – unsurprisingly – money. Even now, in the 21st Century, the US federal government deems state funding for community-based services

“We can agree that, at the very least, people with IDD should have a range of options to support how they wish to live. It seems most of the rest of us do.”



optional, while it requires that states fund institutional services. Even when in the community, supports are structured and financed in most States in such a way as to incentivize larger facilities that are home to more people.

Among the more significant objectives of Health People 2030 is reducing the proportion of people with intellectual and developmental disabilities who live in institutional settings with seven or more people. Data as of 2017 show that 21.5% of adults with IDD continue to live in settings of seven or more. While that's improvement from the 2015 baseline of 22.7%, we have a long way to go to have anyone with an IDD who would choose a smaller setting to actually have access to one. Continued advocacy is essential to expanding options in community living supports for people with IDD. The Arc of the US, with its partners including the American Association on Intellectual and Developmental Disabilities, makes a policy priority of

providing incentives for states and local communities to expand access to individualized community living (American Association on Intellectual and Developmental Disabilities, 2016). Some number of years before becoming President, Joe Biden is quoted as saying the following: “Don’t tell me what you value, show me your budget, and I’ll tell you what you value.” To paraphrase, we need a whole new set of investments in community-based supports that actually allow for smaller, more individualized living environments – and, we need self-advocates, families, friends and professionals to demand nothing less from federal and state governments.

It seems more likely than not, especially in the face of increasing concerns over the Delta variant of COVID-19, that we are not yet out of the pandemic woods. And, it seems, if past is prologue, that people with IDD will continue to fare far worse from the pandemic than their neurotypically developing peers. It bears repeating: There is nothing about an intellectual or developmental disability that, on their own, predisposes people to either contracting or experiencing more severe outcomes from COVID-19. Instead, it appears the greatest risk factors are the very things that we can control. Health status matters. All of the chronic conditions that people with IDD tend to experience in disproportionately higher frequency than people without IDD (Hsieh, K. et al., 2012) can and must be addressed, if not for COVID-19, which has already done incredible damage to the community of people with IDD, then for the next infectious disease event that seems inevitable. People with IDD deserve access to culturally-competent healthcare, and we have an obligation to assure that our healthcare practitioners are trained to an appropriate standard of competence.

In addition, we can agree that, at the very least, people with IDD should have a range of options to support how they wish to live. It seems most of the rest of us do. And, most of us live with two or three or four others only when those others are our family members. Some folks with IDD will choose congregate living options with one or two or three people, while others will not. In any event, it should be the person's choice, not driven by always-scarce funding.

None of these are new issues or new needs. These issues are age-old. But, if a reasonable definition of insanity is continuing to do the same thing while expecting different outcome, then we need to do something different to fully and finally create lasting change.●

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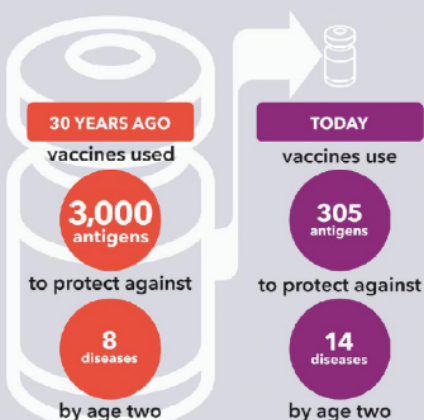
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GETTING PERSON-CENTERED HEALTHCARE

BY JAMES W. MOLD, MD, MPH

Have you ever delayed or avoided seeing a doctor for fear they would find something else wrong or recommend additional tests or treatments? Did you know that the central organizing feature of your medical record is the problem list? Have you ever seen the problem list in your or a family member's medical record? Were you surprised by how long it was? How did that make you feel?

For mostly historical reasons, most medical care today is based upon the following assumptions about health:

1. It is possible to define normal health;
2. Deviations from normal are bad; and
3. Efforts to maintain or restore normality are the best ways to help people live long, enjoyable lives.

Of course, those same three assumptions also apply to cars and watches. Maybe that's why medical care sometimes feels mechanical. It may also be why laboratory tests, X-rays, scans often seem more important to your doctor than knowing how a particular health challenge is impacting your or your family member's life. Unlike cars or watches, people have hopes, values, preferences, goals, and priorities. What is normal for one person is abnormal for another, and what is a problem for one may be an advantage for another. And unlike cars and watches, people often become stronger as they face challenges and overcome obstacles.

The healthcare system is actually trying hard to make care more humane, collaborative, and convenient. Those improvements are often called patient-centered care. However, patient-centered care, as currently envisioned, is driven by the same three assumptions. The focus is still on preventing and correcting abnormalities. The goal is still to make you or your loved one "normal".

What if, instead of asking, "What's the matter with you (or your loved one)?" your doctor first asked, "What matters to you (or your loved one)?" That approach, called person-centered care, changes the focus of attention from fixing things to helping each person achieve their personal goals and reach their full potential. Problems are seen as obstacles, challenges, or opportunities for growth.

Health is viewed as the ability to derive as much enjoyment and fulfillment as possible from life's journey.

Two approaches to person-centered care have been described. The first, called narrative medicine, focuses on each person's life story and the impacts of health-related events on that story. Telling your story can help you see challenges and opportunities more clearly, and once they understand your story, doctors are better able to help you make better medical choices. Many medical schools now teach the principles of narrative medicine, so it ought to be more available in the future.

The second approach, goal-oriented care, assumes that nearly everyone has four major life goals: 1) survival (prevention of avoidable death); 2) engaging in essential and meaningful activities and relationships (quality of life); 3) personal growth and development (meaning, purpose, resilience); and 4) a good death (consistent with one's values and preferences). Each person defines and prioritizes those goals differently based upon their values, preferences, vulnerabilities, and resources and at different points in time. Once a person's goals, priorities, and acceptable trade-offs are clarified, it is possible to determine which medical interventions are likely to be most helpful to them.

Most people value quality of life over the other three goals until they are faced with death. It is only then that they realize how much they enjoy life. Confucius said, "You have two lives. The second one begins when you realize you only have one." Of course, life can sometimes become meaningless or unbearable. At that point, survival is no longer a goal.

The most effective way to delay death is to focus on the most likely reasons a person might die prematurely. A person with swallowing trouble who is at risk for pneumonia, for example, can live longer by taking good care of their teeth and gums where the pneumonia germs live, avoiding contact with infected others, and washing their hands more often. A person with poor balance who is at risk for falls can focus on improving their balance and strengthening their legs and feet. That doesn't mean we should ignore other preventive measures, only that we should focus on the ones with highest impact first.

Activities that are important and meaningful differ from one person to another. Medical care to improve quality of life is most helpful when it focuses directly on a person's ability to participate in



those activities rather than on eliminating abnormalities. It is less important that a person walks “normally” than that they can get where they need to go.

When healthcare promotes recovery of function after an illness or injury, we call it rehabilitation. Occupational therapists and sports medicine physicians use this approach. When the strategies involve developing new skills or improving existing ones, the process is called habilitation. Sports psychologists and fitness coaches use this approach. Goal-oriented care combines both approaches. When medicines are prescribed, the primary focus should be on the activities, not the symptoms, side effects should be tolerable, and the medicines should be stopped periodically to see if they are still needed.

Each of us is unique. Diversity should be encouraged and celebrated. And life is filled with challenges. That’s a good thing. It gives us lots of chances to become stronger, more capable. Goal-oriented healthcare helps each person become all they can be, physically and psychologically. Avoiding or delaying antibiotics for minor infections allows our immune systems to become stronger. Viewing challenging events as opportunities for growth makes us better able to face larger challenges in the future.

End of life planning should not wait until death is imminent because death can occur without warning. In fact, it usually does. There is nothing morbid about admitting that we are all going to die at some point, and when we do, we want it to be a good death. That is more likely to happen if we plan ahead. Everyone with the capacity to do so should complete relevant advance directive documents

(e.g., living will, durable power of attorney for healthcare, do not resuscitate). Those who will be involved in end-of-life decisions, when the time comes, should understand your values and preferences about death and dying.

Until the healthcare system fully adopts a person-centered approach, you will need to help your doctors by doing the following:

1. **Think about the story of your life or your loved one’s life.**

How have particular people, places, and events affected the course of events? What have been the most important challenges? Where does the story seem to be heading? How is it most likely to end? Make sure your doctor hears that story.

2. **Carefully consider your or your loved one’s priorities, and don’t forget what Confucius said about two lives.** Think about things that could put you (or your loved one) at risk for premature death or disability. Consider what you can do now to prevent or delay those undesirable outcomes.

3. **Try to help your doctors focus on the activities and relationships that are most important to you or your loved one.**

4. **View each health challenge as an opportunity to become stronger, more resilient.**

5. **Think about what conditions in life would be worse than death.** Then complete an official advance directive document. If end-of-life decision-making is likely to be problematic, consider creating a durable power of attorney document covering healthcare decisions as well. •

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LESSONS FROM THALIA AND MELPOMENE: DIVERGENT BEHAVIORAL REPERCUSSIONS OF THE COVID-19 PANDEMIC

BY LEY LINDER, DR. RICK RADER AND ANITA LINDER

During the pandemic, we have learned to anticipate the full spectrum of multiple responses in a stressful situation, but it has also highlighted that not all sweeping changes, believed to improve outcomes, result in global positivity for all participants.

Introduction

In March 2020, a coronavirus named SARS-CoV-2, now universally referred to as COVID-19, brought the world, as we knew it, to an abrupt halt. The impact of this global pandemic knew no bounds as countries closed, businesses shuttered, and people exchanged their routine lives for perpetual uncertainty. This upheaval extended to and was magnified exponentially to those in health and human services fields who found themselves in a whirlwind of uncertainty, concern, and change.

When considering the impact, outcomes, and consequences of the “lockdown” resulting from the COVID-19 pandemic, one cannot help but think of the opening paragraph from *A Tale of Two Cities* by the immortal Charles Dickens.

“It was the best of times, it was the worst of times, it was the age of wisdom, it was the age of foolishness, it was the epoch of belief, it was the epoch of incredulity, it was the season of light, it was the season of darkness, it was the spring of hope, it was the winter of despair.”

This paradoxical passage not only provides the perfect analysis of the disruptive state of affairs in 18th century England and France, but also perfectly describes the juxtaposition encountered, observed, and experienced in community group homes for individuals with intellectual and developmental disabilities (ID/DD) during a global pandemic.

For those of us serving people with ID/DD, we were tasked with providing an additional level of protection and care to the most vulnerable people in our communities. A cross-sectional study of 64,858,460 patients across 547 health care organizations reveals that having an intellectual disability was the strongest independent risk factor for presenting with a COVID-19 diagnosis and the strongest independent risk factor, other than age, for COVID-19

mortality (Gleason, et al., 2021). The increased risk to those with ID/DD necessitated strict adherence to protocols related to governmental “stay-at-home” orders, social distancing, and pervasive use of personal protective equipment. These precautionary measures for people with ID/DD meant a prolonged period of decreased access to social systems, suspension of job/work tasks, termination of community-based activities, and changes to support systems (Navas, et al., 2021).

Initially, common feedback from administrative personnel, advocate groups, and healthcare professionals indicated COVID-19 health and safety procedures were causing increases in mental health issues, increases in behavioral concerns, resulting in diminished skill maintenance, and a decline in global function for people with ID/DD. However, as interdisciplinary professionals (i.e., physicians, behavior analysts, direct support professionals) navigated the changes in service delivery systems and adapted to a “new normal”, an antithetical whispering was ushering out a year of darkness and illuminating a spring of hope.

The Pandemic World

People with ID/DD and their supports are not a monolithic group, and the response and reaction to the pandemic varied and changed in individuals over the course of the pandemic. (Keller, S. 2021.). To say, in a wholesale fashion, a group of people’s responses to the pandemic has been poor, or an individual’s response has been detrimental, is to overgeneralize and depersonalize the experience. All individuals have experienced a continuum of responses across time, settings, and personal characteristics during the pandemic. That is to say people’s emotional, psychological, and physical responses have changed and become varied at different points since the onset of pandemic precautions in the spring of 2020.



To draw from the biopsychosocial model, the initial lockdown measures and continued COVID-19 precautionary measures have impacted the integration of physical, psychological, and social dynamics that comprise the totality of all people, including those with ID/DD. The lockdown measures have meant, for a prolonged period, people with ID/DD have stopped working and participating in their communities, centers and services, and have had their routines interrupted (Hughes and Anderson, 2020). The cessation of work, community, and daily routines have impacted social systems, which have led to increased isolation and feelings of detachment. Decreased access to routine medical care (e.g., postponed medical appointments, changes in service delivery) have led to the exacerbation or onset of medical issues, which can impact physical and mental health. Mental health concerns have been at the forefront of concern, as the onset or exacerbation of symptoms of depression and anxiety have been noted across settings, time, and people. The lockdown measures have not only impacted one aspect of a person's life with ID/DD, it has impacted all facets of the individual.

The acknowledgement and illustration of the negative impacts of the COVID-19 lockdown and sustained precautionary measures has been noted in mass media outlets, on conference agendas, and amongst caregivers since the onset of these measures. While it is plausible that changes in daily life due to the COVID-19 pandemic might have increased the risk for incidents, positive reactions may also be possible (Schuengel, et al. 2020).

There are individuals with ID/DD who have shown improvement in a variety of areas (e.g., behavioral stability, psychiatric symptoms, quality of life) as a result of adhering to governmental "stay-at-home" orders and other health and safety measures restricting social interaction and community integration. A long-held, pervasive assumption is every person with ID/DD "thrives" in community

settings, and socialization is a preferred activity. As the COVID-19 pandemic wore on, a pattern among some individuals developed that noted a reduction in problem behaviors, a decrease in psychiatric symptoms, and (surprisingly) instances of joy were being observed. In some individuals, the decrease in problem behaviors and psychiatric symptoms were leading to the justification for discontinuation of behavior analytic services, reduction or cessation of psychotropic medications, and a general reduction in the need for restrictive programmatic supports.

The Pandemic Person

To highlight the ways in which a person may have experienced positive impacts from the COVID-19 pandemic seems counterintuitive on the surface, particularly to note a person may have been *happier* during a lockdown. People with ID/DD have different experiences related to their social interactions, daily schedules, and engagement in leisure activities. The impact of COVID-19 precautions changed decades-long approaches to care that were fundamentally rooted in social interaction, daily schedules emphasizing community engagement, and leisure activities that incorporated both social and community involvement.

Individuals with ID/DD are more likely to exhibit poor social skills and routinely find themselves in situations with large numbers of people (i.e., day programs, community events), novel social scenarios, and interacting with people who do not feel comfortable around them. It is not uncommon for individuals with ID/DD to have difficulty with starting conversations, extending conversations, and/or having idiosyncratic social communication skills. These dynamics require a familiarity with the individual in order to achieve effective communication and social interactions. Additionally, the aforementioned characteristics can also lead to

shortened, negative, and/or a decrease in the opportunity for social interactions in community settings.

The COVID-19 precautions, which led to decrease in social interactions and community involvement, shrunk the size and demands related to social systems for many people with ID/DD. The reduction in size of social systems, and associated demands led to a more predictable, manageable, and tolerable presentation of social engagement. The reduction of size of social systems may follow from suspending daily obligations such as work, freeing time for leisure activities and from decreasing numbers of people invading the privacy of group homes. (Schuengel, et al. 2020).

For individuals living in a residential group homes, COVID-19 precautions allowed for social systems where they had familiarity with all people they were interacting with (peers and staff), as well as the skills and requisite idiosyncratic knowledge to interact positively within these smaller social systems. This actually increased the opportunity for successful and naturally reinforcing social interactions.

Beyond social systems, COVID-19 precautions led to changes in daily routines. Pre-pandemic schedules were rife with task demands and instruction. The changes in daily scheduling led to lower stimulation, lower demand environments, which allowed individuals to have less strenuous and arduous daily schedules. There are many environmental/sensory reasons why the environments were felt to be inhospitable, such as loud and crowded work environments, the restriction of free movement in certain settings, and mandated, pre-selected activities.

In residential group home settings, daily scheduling can be dominated by ADL tasks, skill acquisition in work and residential settings, and pre-determined activities focused on socialization and community engagement. Upon awaking, many individuals are prompted to immediately engage in ADL tasks, which can be inherently difficult, given skill deficits. In some instances, they are then prompted to attend day programs or work settings where they are steadily prompted to engage in skill acquisition and/or work tasks for six to eight hours. Upon returning home, prompting-based tasks related to skill acquisition, task completion, and ongoing ADL tasks are continued.

A day in the life of a person with ID/DD is characterized by repeatedly engaging in difficult tasks accompanied by ongoing instruction (and correction!). At the end of the day, people with ID/DD are mentally, physically, and emotionally fatigued. The COVID-19 pandemic put an immediate halt to the excessive, continuous, and difficult task demands dominating the daily lives of individuals with ID/DD.

After examination of a person's daily schedule and the acceptance a person is likely to be fatigued at the end of the day, it is not unreasonable to present the person with leisure activities. However, the presentation of leisure activities, which frequently involve socialization and community activities, can be daunting. Given possible skill deficits, engagement in community and social based activities can be difficult and require high demands from the individual. COVID-19 precautions have highlighted the need for indi-

viduals to have robust leisure skills that extend beyond community outings and social engagement to include *independent* leisure skills. Additionally, leisure skills for people with ID/DD should be expanded to include function-based activity scheduling across settings, people, and time, while being tailored to the individual's preferences.

It should not be assumed that every person is desirous of leisure activities focused on socialization and community engagement. It is not uncommon, nor problematic, for a person to enjoy home-based activities and/or independent leisure activities. Mandating social and community-based activities can be antithetical to the person's personal choice. Furthermore, if the person has difficulty engaging and participating in these environments, it can be a continuation of task demands, instructional periods, and, simply put, more work.

Interdisciplinary Responses

Behavior Analysis: The COVID-19 pandemic and associated precautions have put an unusual spotlight upon the behavior of

people and the impacts of social isolation, changes in routines, and reduction in physical activity. All these factors create a risk of the appearance of challenging behaviors that negatively affect the emotional wellbeing and quality of life of people with ID/DD (Navas, et al., 2021). For those people living in congregate living settings, such as long-term care communities, mainstream media emphasized the behavioral and psychological impact of COVID-19 with headlines such as, "Distress in seniors surges amid coronavirus pandemic" (CNN, May 25, 2020). For those with ID/DD, the mainstream media focused on the lack of access to care, poorer healthcare outcomes, and increased mortality, as seen in the NPR article titled "COVID-19 Infections and Deaths are Higher Among Those with Intellectual Disabilities" (Shapiro, J., 2020).

As headlines flickered across screens through the fall of 2020, those in health and human service fields, were discussing the psychobehavioral impacts of lockdown precautions stretching beyond six months and through the upcoming winter. As discussions spread across disciplines, settings and caregivers, a common theme developed – behavior. "How was John coping with not seeing his family every weekend?" "What has Jane been doing since she can't work?" "How will people react when they can't socialize? What about skill development? And routines! And schedules!"

Predictably, an array of negative behavioral changes was observed among individuals with ID/DD confined to their group homes as a result of the COVID pandemic "lockdown". Direct Support Professionals, behavioral analysts, as well as counselors and therapists reported dramatic increases in anxiety, stress, aggression, self-abusive behaviors, depression, confusion and isolation. The pandemic created strife, distress, and even decline in function for people with ID/DD. The impact of the COVID-19 precautions has been disproportionately strenuous for those with ID/DD, as the duration, parameters of, and rigidity of precautions has been more pervasive for this population (Constantino, et al., 2020). This has led to an increase in the likelihood of negative impacts, such as problem behaviors and psychiatric symptoms.



As the pandemic precautions continued through the winter of 2020 and into the new year, there were unlikely and unanticipated patterns surfacing. As interdisciplinary teams continued to work to address the changes in residents, employees, and caregivers, patterns began to emerge with some individuals showing improvement with previously identified problem behaviors decreasing and socially acceptable, desired behaviors increasing.

For example, MH is an individual who has a long history of having difficulty with appropriate social interaction with peers, which would often lead to raising his voice, cursing, making threats of physical harm, and occasional physical aggression. These behavioral concerns were heavily concentrated in the day program setting, with decreased frequency and intensity of these behaviors in the residential setting. In the past and during long-term periods of behavioral stability, MH successfully completed and enjoyed a job performing lawn care with his peers, with staff supervision and support, which was afforded to him through a day program specifically supporting individuals with ID/DD. This job allowed MH to have freedom of movement not only in his immediate environment, but also access to the reinforcing social attention in a smaller, more manageable environment that decreased the need for competition with peers for the desired reinforcement.

Prior to COVID-19 pandemic, MH moved to a new residence, which necessitated a move to a new day program that did not support employment opportunities with the type of job characteristics MH preferred and excelled. The new job was in a large building with approximately 100 other individuals, in a warehouse environment, where his piecemeal job demands he sit at a table, and work independently for approximately 6 hours per weekday. Although MH has room for improvement with his social skills, he is highly reinforced by social attention and would frequently leave his “designated area” to find peers to interact with. Verbal prompts from staff members and/or the resulting negative interpersonal interactions with peers led to routine instances of problem behavior.

Access to a community center with specific supports for his preferred type of job led to MH’s long-term success. The ability for MH to access a preferred job through disability specific resources, which supported his preferences, while being able to appropriately manage his needs was pivotal to his success. The decision to eliminate choice from MH’s employment led to an increase in behavioral instability. The means of eliminating the stress of the non-preferred job and setting was not rooted in MH’s choice, but in pandemic precautions that removed known antecedents.

Behavior data collected from October 2019 to April 2021 for targeted and non-targeted problem behaviors (as indicated) shows a clear reduction in all aforementioned problem behaviors. For the three months preceding the COVID-19 pandemic (December 2019, January 2020, and February 2020), MH averaged 9.67 documented behavior incidents per month. For the three months after the initial COVID-19 lockdown in March 2020 (April, May, and June 2020) MH averaged 1.67 documented behavior incidents per month. The next

quarter (July, August, September 2020) exhibited a slight increase in the average number of documented problem behavior incidents with 3.33 per month. The next quarter (October, November, and December 2020) exhibited a reduction in the average number of documented problem behavior incidents with two per month.

MH returned to a staggered, part-time day program attendance in February 2021 and full time in March 2021. The first quarter of 2021 has shown an increase in the total number of problem behavior incidents with an average of 5.67 per month. The total number of documented behavior incidents for March 2021 was nine, which is slightly less than the pre-pandemic average of 9.67. Preliminary April 2021 data indicates 11 total documented incidents of problem behavior with the onset of a new behavioral concern of sleeping at his work station.

The interdisciplinary team has discussed the following dynamics, which may have accounted for MH’s behavioral progress during the COVID-19 pandemic precautions:

- *Difficulty socializing-smaller, more predictable social systems have allowed for increased ease of navigating social interactions*
- *Over stimulation in work setting*
- *Long periods of task demand, instruction*
- *Not having to perform a non-preferred job task in a non-preferred setting*
- *Forced community integration and socialization*

Psychiatric: The unforeseen pandemic quarantine served to validate long-held suspicions that a number of

individuals with ID/DD tend to thrive and live happier lives when not put in situations that force them to engage in community-based activities, mandated job attendance, and social focused leisure activities. Psychiatric teams serving adult individuals residing in community-based group homes, found some individuals had significantly less physically aggressive (PA) and/or self-injurious behaviors (SIB) when remaining in their residences during the quarantine. In some cases, these psychiatric teams were able to reduce psychotropic medications. Conversely, these teams continued medications for some individuals in anticipation of their return to community-based day programs. The teams were concerned if medications were reduced, the behaviors would re-emerge once the day program schedule resumed.

The contraindications of medication reductions due to specific settings clarified the concept that individuals may be medicated in order to meet the demands of community integration and job participation. Clearly, this is juxtaposed to the therapeutic goals for the individuals, specifically as outlined by person centered planning, in addition to state and federal regulatory mandates. As a result, there needs to be an increase in interdisciplinary team discussions to focus on alternate plans for individuals who are clearly stating through their behaviors that they prefer not to engage in some community-based activities. The discussions are ongoing and continue to be difficult, given providers agencies continue to struggle with what the “new normal” will be, in conjunction with demands from state and federal mandates.

“As the pandemic precautions continued through the winter of 2020 and interdisciplinary teams continued to work to address the changes in residents, employees, and caregivers, patterns began to emerge with some individuals showing improvement with previously identified problem behaviors decreasing and socially acceptable, desired behaviors increasing.”

To illustrate the negative impacts of forced community integration that have been highlighted by COVID-19 precautionary restrictions, the case of CA, who is a 30-year-old female, diagnosed with moderate ID, autism, and has congenital blindness will be discussed. CA possesses adequate receptive communication skills to follow requests, but her expressive communication is limited to short phrases.

She has a long history of PA (striking others) and SIB (hitting her face and pressing on her eyes with her hands), which has resulted in injury to herself and others in the past. Additionally, these behaviors were also accompanied by stripping off her clothes, screaming, and general disruption to the environment. Behavioral data clearly indicates a greater frequency when she was in the day program setting versus in her home. Pre-pandemic, the behaviors she exhibited at the residence often occurred in the early morning when she was being prompted to get dressed and during transport to the day program.

At the most extreme, she was exhibiting an average of 200 + incidents of SIB per month and 40 + instances of PA per month. At the most recent quarterly psychotropic medication review in spring 2021, the behavioral data revealed for the last six consecutive months she has had fewer than 70 incidents of SIB per month and less than 20 incidents of PA per month.

She enjoys listening to music in her room, sensory integration activities, and outdoor walks preferably with the 1:1 attention of a staff person. She has been able to engage in these activities more often during the pandemic. Although SIB and PA persist, the PA is almost half of the pre-pandemic rates and SIB is only one third of the pre-pandemic frequencies. Even in the face of noted improvement in the absence of mandated day program attendance and community integration, the psychiatric team has opted against medication reduction, given she will be returning to the day program in the near future.

Direct Support Professionals

The clinical perspective of behavior analysts and psychiatrists allows for data-driven analysis of the impact of the COVID-19 pandemic on individuals with ID/DD. Members of the interdisciplinary team of critical importance are direct support professionals (DSPs), who are the backbone of the service delivery and support systems for those living in residential group home settings. Although largely anecdotal, information obtained through discussion, input in team meetings, and working alongside DSPs has illuminated experiences that mimic the individualized and personal responses of people to the COVID-19 pandemic.

Direct Support Professionals fall within the large categorization of healthcare providers whose job descriptions thrust them to the front lines to fight an invisible threat. Access to personal protection equipment was often times limited, long-standing staffing shortages were amplified, and the constant companions of confusion and worry shadowed them through every shift. The insights from these members of the interdisciplinary team are invaluable in identifying characteristics amongst the ID/DD population in response to the COVID-19 pandemic.

Conversations with DSPs have yielded varying opinions on the responses of the individuals living in residential group home settings. The most common difference in responses was related to the level of care the DSP primarily worked in. DSPs who worked with individuals who had more robust skill sets and living in settings allowing for greater independence (e.g., apartments), tended to express increased negative impacts on individuals with ID/DD. DSPs who worked with individuals requiring the highest levels of care reported less pervasive, but not non-existent, negative impacts from COVID-19 restrictions.

The greatest continuum of responses from DSPs, based on setting, were related to individuals with more moderate skill deficits who were more likely to be independent in activities of daily living (e.g., bathing, grooming, eating), but need assistance with executive functioning skills, such as problem-solving, organization, and planning. DSPs reported varying differences within this subset of individuals, but also varying responses within the person. They noted the person could have difficulties comprehending the restrictions,

difficulty adapting to the changes in routine, and difficulty with novel activities and task demands – to name a few characteristics. Interestingly, and as Dr. Seth Keller noted previously, these characteristics would change throughout the course of the pandemic (Keller, S., 2021).

Another common theme discussed by DSPs regarding responses of persons with ID/DD to the COVID-19 pandemic was what the person's preferences were. Did the person enjoy their job? Did they enjoy social interactions? Did they have

community activities they routinely participated in (e.g., religious services, romantic relationship, home visits)?

A DSP interview conducted by a Board-Certified Behavior Analyst (disclosure: co-author) in May 2021 with a House Manager working in residential group home highlighted the difference within individuals living in the same home, which focused on activity preferences. The interviewee described a scenario where three (of the four) individuals living in a home preferred a more “relaxed home-life” that focused on their independent leisure skills, such as watching movies, playing video games, and community activities (e.g., going out to eat, going to flea markets). The other individual was highly reinforced through social interaction and robust activities, which included having a girlfriend, having a job (supported through the day program), and socializing with his peers. The interviewee highlighted the dichotomy within this home of responses to the pandemic that was not rooted in the reduction/cessation of problem behavior, but in overall happiness. The gentlemen who preferred a more relaxed approach to social and community engagement appeared to have an increased quality of life during the pandemic precautions.

An observation of the characteristic(s) of the type of individual who DSPs were more likely to note behavioral and psychiatric improvement during the COVID-19 pandemic were individuals who were qualified as “high-management”. The definition of high management was being a person who historically exhibited more frequent, higher intensity behaviors that were more likely to jeopardize the health and safety of themselves or others.



A DSP interview conducted by a Board-Certified Behavior Analyst (disclosure: co-author) in May 2021 with a House Manager working in residential group home qualified as high-management expressed “surprise at how well our men have done (during the COVID-19 pandemic).” One interviewee noted the approach to care during their 17 years in the field has been focused in training, community involvement, and socialization. The interviewee continued to say, “our guys don’t want to do all the stuff (we are told to do with them).” The context of this person’s comments were in the midst of a discussion about activity restriction as a result of COVID-19 precautions, and how staff worked to continue to allow access to preferred items and activities—such as going to drive-thru restaurants, car rides, and making lists for certain stores so staff could go and access needed/wanted items.

Over the course of several weeks in May 2021, these DSP interviews identified several themes and hypothesized reasons for the differences between individuals, settings, and experiences as being the following:

- *Ability to comprehend the gravity of the global pandemic*
- *How significantly pandemic restrictions impacted day-to-day life of the person*
- *Skill-sets of individuals allowing for adaptation and changes*
- *Personal preferences for schedule, job/work participation, and leisure activities.*

Person-Centered Planning, HCBS Final Rule, and Pandemic Restrictions

The prevailing fundamental approach to service provision in the field of ID/DD is person-centered planning. This now-ubiquitous approach is best described as “being driven by the person receiving services, choosing who participates in the planning process and the delivery of services, as well as individually identified goals and achievement of outcomes in the most integrated community setting. Services should be delivered in a way that reflects the person’s individual choices and contributes to their overall health and welfare (TN DIDD, 2021).” This approach has been cemented as the philosophical bedrock for all service providers through the CMS Home and Community Based Services Settings Rule, also referred to colloquially as the “Final Rule.”

The HCBS Final Rule can be conceptualized as the minimum requirements set forth by CMS for both residential and day service providers for individuals whom Medicaid pays for rendered services. In brief summation, the HCBS Final Rule seeks to ensure that recipients of Medicaid services have a choice in all aspects of their lives, their rights are protected, and have access to the community in the same fashion as citizens without disabilities.

The underlying assumption for the development and implementation of the HCBS Final Rule indicates the best place for all persons with ID/DD to experience life is in the most integrated community settings available. After completing a literature review of 61 studies of the impacts of deinstitutionalization of people with intellectual and psychiatric disabilities, Bredewold, et al. noted that it is not clear if people living in community settings are experiencing real inclusion

(2018). A federal mandate removing access to community centers with pervasive access to necessary adaptive equipment, leading to fractured health care service provision, and forced community integration can be contradictory to person-centered goals of decisions “contributing to the overall health and welfare (of individuals)”, but also the HCBS Final Rule premise of “optimizing autonomy and independence in making life choices.” Furthermore, this all-encompassing assumption propagated by the HCBS Final Rule has been exposed as too broad of a “brush stroke” during the COVID-19 pandemic, as some individuals have shown improvement in not only behavioral and psychiatric stability, but also in their quality of life and overall happiness, through the reduction of forced community integration.

Criticisms

The two main points of this article state the HCBS Final Rule is not an all-inclusive approach that is effective for ensuring a true person-centered approach to supporting all individuals with ID/DD, in addition to noting that the COVID-19 pandemic and associated

precautions was not responsible for universally poor outcomes for all people with ID/DD. Although these are not novel, revolutionary ideas given the whispers amongst service providers and interdisciplinary professionals, the statements of this article do bring us back to the dichotomy illustrated by Mr. Dickens, “it was the age of wisdom, it was the age of foolishness.”

These issues have been whispers for many years, as they are controversial and perceived as being a

promotion of “institutionalism”. These ideas are not indicative of a desire to return to horrors revealed to the world through the images such as those of Willowbrook State School in the 1970s. The need to ensure people with ID/DD have equitable access to healthcare and employment, are free from discrimination, and afforded their unalienable rights is an assertion that elicits cohesion and solidarity among all those working with and serving those with ID/DD. However, these minimal standards can be achieved in manners beyond the HCBS Final Rule where specialized services, community centers, and residences for individuals with ID/DD are not inherently exclusionary, non-preferred, or inadequate. One can simply look to the socially accepted long-term care service providers (e.g., aging demographic) for evidence of the approach of caring for individuals with similar needs within a specific demographic.

Additionally, recognizing that not every person with ID/DD is desirous of daily schedules and leisure activities rooted in community involvement and socialization is not indicative of poor service provision. A common retort to the views expressed in this article can be surmised by “If your individuals are not thriving in the community, it’s because you (as a provider) don’t have the skills, imagination, or vision to provide them with the optimal situations for them to find their place.” Making the assumption that the true desire of people with ID/DD to be subjected to forced community integration is in direct conflict with the stated goals of person-centered planning and the resulting federal mandates outlined in the HCBS Final Rule. Too often, the person-centered choice is decided

by well-meaning professionals and advocates who perceive the “community” is best for everyone.

The lasting purpose of the statements outlined is not to seek to dismantle a fundamental approach and service delivery system which works for so many, but simply to revisit our pledge for “self-determination.” As service providers, we all possess a progressive outlook which seeks the highest quality of life for those with ID/DD. We are simply seeking to illuminate and revisit the prevailing notion that every person with ID/DD benefits or, more important, desires the wholesale enforcement of forced community integration.

Future Considerations

This article examines and explores the phenomenon of psychobehavioral stability and global progress of some individuals with ID/DD during the COVID-19 pandemic. The examination of the impacts of COVID-19 lockdowns and sustained precautionary measures has highlighted the unintended consequences of forced community integration. These consequences can include, but are not limited to, poor social outcomes, increased isolation, decreased access to necessary healthcare, a decline in global functioning, and reduced quality of life for the person. As a community of service providers, the lessons learned from the COVID-19 pandemic may present more constructive ideologies which are more diligent in the provision of services to address individualized need predicated by actual choice.

Beyond the identification of the divergent behavioral repercussions of the COVID-19 pandemic, this article is a call to action to reexamine what we think defines a meaningful life for people with complex disabilities. During the pandemic we have learned to anticipate the full spectrum of multiple responses in a stressful situation, but it has also highlighted that not all sweeping changes, believed to improve outcomes, result in global positivity for all participants. Lastly, we, as a community of service providers, should revisit person-centered thinking and verify that it centers on the authenticity of the person with the goal of promoting real choice.

As we conclude, and since it has not been referenced in the body of this article, readers may have overlooked or discounted the title relating to Thalia and Melpomene. This was not an oversight but the decision that it would be best served as a parting message. Thalia and Melpomene are better known as the theatrical masks depicting comedy and tragedy. They became part of the theatre in ancient Athens where they helped actors to clearly reflect and project their emotions. The large faces and exaggerated expressions helped them convey their emotions to all the open-air theatre goers, including those seated far from the stage. The mask of the smiling Thalia was the muse of comedy while the frowning Melpomene was the muse of tragedy. Of particular interest is that the masks are always portrayed together. The two masks represent the two basic emotions of joy and sorrow. We believe this is symbolic of the two distinct emotions displayed by individuals with intellectual and developmental disabilities as observed and reported during the recent and ongoing COVID-19 pandemic. We have seen both emotions displayed, exhibited and addressed, depending on individual personalities, resilience, personal choices, supports, response to changes and accommodations in altered routines, settings and goals.

Like theatre-goers who can freely choose to attend a comedy or tragedy, we feel that the greatest tribute to personal choice and the jewel of “person centered planning” is for it to be truly person centered. •

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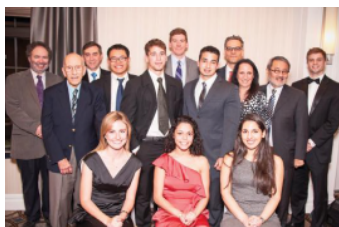
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TALKING ABOUT COVID-19: **6 TIPS FOR PARENTS, FAMILY MEMBERS, AND CAREGIVERS**

BY KAREN REMLEY, MD, MBA, MPH, FAAP

People with intellectual and developmental disabilities (IDD) face unique challenges and are more likely to get very sick from COVID-19. Throughout the COVID-19 pandemic, parents, family members, and caregivers have been working hard to help the people they care for stay healthy and safe during this difficult time.

Over the past few months, the Centers for Disease Control and Prevention (CDC) has asked caregivers to share what they have found helpful when talking with their loved ones with IDD about getting a COVID-19 vaccine, getting tested, washing hands, practicing physical distancing, and wearing a mask..

CDC hosted a series of discussions with adults with IDD and their caregivers, most of whom were family members. The findings from those discussions helped inform the development of a new suite of CDC materials, including videos, posters, stories, and activities. The aim of these materials is to help caregivers talk with their loved ones with IDD about what to expect when getting a COVID-19 vaccine or test and how to stay safe if they are not fully vaccinated. •

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LET'S TALK : TOOLS TO START THE CONVERSATION

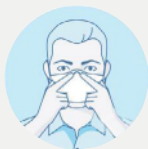


COVID-19 materials for people with IDD and their caregivers
www.cdc.gov/ncbddd/humandevelopment/COVID-19-Materials-for-People-with-IDD.html

Additional COVID-19 information for people with disabilities
www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-disabilities.html

CONVERSATION STARTER : SIX TIPS FOR PARENTS, FAMILY MEMBERS, AND CAREGIVERS

Below are tips and resources to help parents, family members, and caregivers make tough conversations about COVID-19 a little easier.



TIP 1: MODEL AND EXPLAIN WHAT YOU'RE DOING TO STAY SAFE

When you do things like wearing a mask if you are not fully vaccinated or washing your hands, try pointing out and talking about what you're doing and why you're doing it. For example, as you put on your mask, say, "I'm putting my mask on because I'm not fully vaccinated yet and I'm about to be around other people." You can also watch CDC's COVID-19 videos for people with IDD together to see specific ways to stay safe – like wearing a mask – and apply these to your daily routine.

"Sometimes, I think as caregivers, we get so used to, 'Come on, let's go!' and you do something automatically like put on the mask, but you forget to tell them, 'Okay, this is why we are putting that on' and actually modeling what you're doing. I think that's a good reminder."



TIP 2: SHOW EMPATHY BY ACKNOWLEDGING HARD THINGS

Some ways to prevent COVID-19, like getting the vaccine or wearing a mask, can be hard for people with sensory challenges. Show that you understand what they are going through. Then, remind them that everyone needs to take actions to stay safe from COVID-19. When possible, see if there are small changes that could make these actions easier. For example, try out a few different styles and fabrics of masks.

"We've had to model how to wear masks to keep safe, acknowledging how it might hamper your breathing a little bit or make you feel uncomfortable or make you hot, but explaining why we had to. And acknowledging his routine, which is totally broken from what we would normally do. Once he had his shot, he was kind of nervous before having it, and we just let him know it was going to be okay."



TIP 3: GIVE REMINDERS TO STAY SAFE WHEN LEAVING HOME

If you or your family member are not yet fully vaccinated against COVID-19, remind them to stay physically distanced from others as you're getting ready to leave home. Be sure to use the same words every time. For example, you could say, "When we go out, keep a safe distance between yourself and other people." CDC's COVID-19 posters for people with IDD can help the person you care for remember to practice safe habits. Post them in the kitchen, living room, or other places where you spend time together. You can also share them in schools, workplaces, and other group settings.

"Praise him when he's doing something right, like 'Oh, I like how you're wearing your mask, you're keeping me safe and you're keeping you safe!' or 'I like how you're washing your hands and you're doing such a good job. That keeps us from getting sick.' So just a lot of reinforcement helps. Posters can also help reinforce what we're trying to teach at home. Just showing it's not just us, that other people have to do it too."



TIP 4: IDENTIFY AND ACKNOWLEDGE CHANGES IN ROUTINE

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

"When we were supposed to go on Thanksgiving vacation, we had to let him know ahead of time that we wouldn't be going because he's in a routine and he knew what we were doing, so we had to explain that. A lot of the things that he used to do, like Special Olympics, we had to explain why we can't. We really had to talk a lot about why you can't today or why you have to wait so many days, just a reassurance every day that you will get back there."



TIP 5: EXPLAIN WHAT TO EXPECT AHEAD OF TIME

When you are getting ready to go to a new place, explain what to expect and point out anything that might be different than usual because of COVID-19. For example, as you are getting ready for a doctor's appointment, you could mention that everyone will be wearing a mask, including the doctor. CDC's social stories and interactive activities for people with IDD can be a great way to prepare for new situations like these. You can read the social stories together to reinforce habits and learn what to expect in new situations, like getting a COVID-19 vaccine or test. Some materials are in "fill-in-the-blank" or "cut-out" formats to help personalize the stories and make them easy to review together.

"As things have eased up, if I'm a caregiver, Special Olympic bowling started a week ago, and there are certain expectations that they still have to wear masks and they are still supposed to distance. We talked about that, two weeks in a row. So, I think that's really important too—explaining what's going to happen when we get there."



TIP 6: EASE THEIR WORRIES

It's normal to feel scared or anxious about COVID-19 – especially when so much is out of our control. If the person you care for is feeling worried, remind them that there are things they can do to stay safe. The most important thing is getting the COVID-19 vaccine, and until they are fully vaccinated, they can protect themselves and others by wearing a mask, keeping a safe distance from others, and washing their hands.

"I explained to her that it's important that you get the shot so that you can do things other than staying in the house and this will help you and keep you from getting sick. She wants to go back to her day program, and I told her that getting the vaccination will help her get back to her day program quicker. I took her with me when I got my shot. She watched me get mine and she saw that there was no fear involved."

A LESSON FOR RAISING A HEALTHY CHILD



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THE SUPREME COURT UPHELD THE ACA (YET AGAIN!)

WHAT IT MEANS FOR CHILDREN WITH SPECIAL HEALTHCARE NEEDS AND THEIR FAMILIES

BY LAUREN AGORATUS, M.A.

WHAT WAS THE CASE ABOUT?

In some states, challengers to the Affordable Care Act (ACA) sought to dismantle it on the basis of unconstitutionality. On June 17, 2021, the Supreme Court decided that those who challenged the ACA “had no legal standing to file their lawsuit seeking to nullify a law...”¹ The Supreme Court’s 7-2 decision reassured families of children with disabilities that the ACA remained the “law of the land.”

REACTIONS FROM ADVOCACY GROUPS

SPAN Parent Advocacy Network issued a statement in support of the ACA. It read in part:

- Since its inception, Obamacare has provided coverage for more than 20 million Americans and saved tens of thousands of lives.

- It has protected people with pre-existing conditions from discrimination – including common medical issues like diabetes, asthma, cancer, Alzheimer’s, and even pregnancy! This includes providing protections for essential health benefits, including prescription drugs, maternity care, and behavioral health.
- States receive \$135 billion in funding for their healthcare marketplaces, Medicaid, and the Children’s Health Insurance Program (CHIP).
- Medicaid expansion has led to better access to care and health outcomes for 12.7 million lower-income individuals and their families in 36 states.
- Healthcare has become more affordable overall.
- Women can no longer be charged more for insurance and are guaranteed coverage for services essential to women’s health.
- Millions of disabled Americans have been protected from arbitrary annual or lifetime coverage limits.

1. <https://www.reuters.com/business/healthcare-pharmaceuticals/us-supreme-court-rejects-republican-challenge-obamacare-law-2021-06-17/>

Little Lobbyists had a blog and parent story on special needs kids and the ACA. In the blog, the first parent was concerned if they could afford the best medical treatment. The father's goal was to give his son "the best chance at a healthy, independent life... Without bankrupting our family..." He continues to state that his son had multiple hospital stays and surgeries resulting in "multi-million dollars in medical bills."

The second family story, also from a father, notes his son was born premature, spending months hospitalized. He cites that before the ACA, many insurance plans had coverage limits over a lifetime, which he would have met or even exceeded just for the first hospital stay. The ACA was passed literally days before his son's birth.

The Arc national also put out a statement in support of the Supreme Court decision. In part it reads:

"The ACA is critical to the lives of people with disabilities... Without it, millions of adults and children would lose their health coverage, or it would become unaffordable, during an unprecedented time of health risk and uncertainty, as well as economic instability... This uplifting moment is about the millions of people with disabilities, their families... that rely on the ACA for access to health coverage for preventative care, to maintain good health, and secure vital medical treatment. This moment is about protecting them from discrimination."



SMALL BUT MIGHTY: The Supreme Court ruled 7-2 that the plaintiffs lacked standing to challenge the health care law. This was the third challenge to the ACA rejected by the Court, and a huge relief for many families.

ACA PROTECTIONS FOR CHILDREN WITH DISABILITIES

In addition to the elimination of annual/lifetime "caps", other benefits include protections for pre-existing conditions. This means that a child with a certain condition can't be dropped by the insurer. Mental health and behavioral health are key components of the ACA, particularly important to parents of children with mental illness or developmental disabilities. Therapies like physical, occupational, and speech therapy are covered for children. Prior to the ACA, many insurance companies denied habilitative therapies for children (unlike rehabilitative for adults) as "developmental or educational". Wellness services, such as immunizations, are important for all children and are now free.

The recent Supreme Court decision allowed families of children with special health care needs to breathe a collective sigh of relief. These enduring protections will allow children with disabilities to continue to more easily get the medical care that they need – and their families to afford that care. •

HERE TO STAY : REACTION TO THE ACA RULING



SPAN PARENT ADVOCACY NETWORK STATEMENT

<https://spanadvocacy.org/blog-post/span-applauds-supreme-court-for-decisive-obamacare-ruling>



Advocating for Kids with Complex Medical Needs & Disabilities

LITTLE LOBBYISTS

Blog and parent story

<https://littlelobbyists.org/blog/2021/6/22/a-reflection-on-the-healing-power-of-the-affordable-care-act-ncsp-by-peter-witzler>

www.vox.com/policy-and-politics/2017/6/21/15842780/senate-health-care-lifetime-limits



<https://thearc.org/the-arc-released-the-following-statement-on-the-us-supreme-courts-ruling-in-california-v-texas>



NATIONAL DISABILITY NAVIGATOR RESOURCE COLLABORATIVE

Child with Special Health Care Needs factsheet

<http://nationaldisabilitynavigator.org/ndnrc-materials/fact-sheets/population-specific-fact-sheet-child-with-special-health-care-needs/>

TO LEARN MORE:

HHS: Statement by HHS Secretary Becerra

www.hhs.gov/about/news/2021/06/17/statement-hhs-secretary-xavier-becerra-us-supreme-court-decision/index.html

CMS: Statement by CMS Administrator Brooks-LaSure

www.cms.gov/newsroom/press-releases/statement-centers-medicare-medicaid-administrator-chiquita-brooks-lasure-us-supreme-court-decision

Community Catalyst: Press Release

www.communitycatalyst.org/news/press-releases/supreme-court-upholds-aca-preserving-care-for-millions

Georgetown University Center on Health Insurance Reforms:

A Great Day for the Affordable Care Act

<http://chirblog.org/a-great-day-for-the-affordable-care-act>

Health Affairs: Supreme Court Rejects ACA Challenge; Law Remains Fully Intact

www.healthaffairs.org/doi/10.1377/hblog20210617.665248/full

ABOUT THE AUTHOR:

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



Advance Payments of the 2021 Child Tax Credit

THE BASICS

WHAT?

For tax year 2021, families claiming the Child Tax Credit will receive:

- Up to \$3,000 per qualifying child between the ages of 6 and 17 at the end of 2021
- Up to \$3,600 per qualifying child under age 6 at the end of 2021

The total of the advance payments will be up to 50 percent of the Child Tax Credit.

WHO?

The maximum credit is available to taxpayers with a modified adjusted gross income of:

- \$75,000 or less for single filers and married persons filing separate returns,
- \$112,500 or less for heads of household, and
- \$150,000 or less for married couples filing a joint return and qualifying widows and widowers.

Eligible taxpayers don't need to take any action now other than to file their 2020 tax return if they haven't done so. Taxpayers can benefit from the credit even if they don't have earned income or don't owe any income taxes.

WHEN?

Advance payments of the 2021 Child Tax Credit will be made monthly from July 15 through December 15 to eligible taxpayers who have a main home in the United States for more than half the year.

HOW?

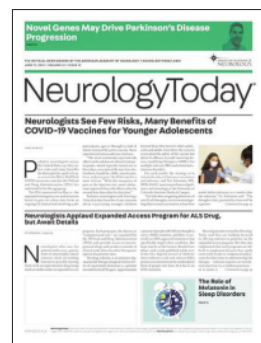
- Advance payments will be calculated and paid automatically.
- Eligible taxpayers who don't want to receive advance payment of the 2021 Child Tax Credit can unenroll from payments.
- Eligible taxpayers who don't normally file a tax return can register for the monthly advance payments using the **Non-filer Sign-up Tool**.

Visit [IRS.gov/childtaxcredit2021](https://www.irs.gov/childtaxcredit2021) for more information and to access the online tools.

THE IMPETUS BEHIND AAN'S NEW SECTION ON ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

BY GINA SHAW

ARTICLE IN BRIEF



Neurologists have established a new section at the AAN to help provide resources and training to support the needs of children, and adolescents with intellectual and developmental disabilities to transition as they transition to adult care. Here, Seth M. Keller, MD, and Bhooma Aravamuthan, MD, DPhil, discuss the section's plans, priorities, and progress.

journals.lww.com/neurotodayonline/toc/2021/06170

Babies, children, and adolescents with intellectual and developmental disabilities (IDDs) related to conditions such as epilepsy, cerebral palsy, and autism commonly receive care from pediatric neurologists. When these individuals reach adulthood, however, adult neurology has generally been ill-equipped to provide the appropriate care for them.

“Historically, these individuals often did not live long enough to reach adulthood, which is part of the reason for a lack of focus on people with IDDs in adult neurology”, said Seth M. Keller, MD, a neurologist in private practice with Neurology Associates of South Jersey, past president of American Academy of Developmental Medicine and Dentistry (AADMD), co-president of the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) and chair of the AAN's new section for Adults with Intellectual and Developmental Disabilities. “

Today, people with IDDs and neurologic complications are living well into adulthood, but adult neurology hasn't caught up with them.”

That's the impetus behind the creation of the new AAN Section, which focuses on the need for neurologist-centered care for adults with these disabilities.

Dr. Keller and section Vice Chair Bhooma Aravamuthan, MD, DPhil, assistant professor of neurology in the division of pediatric neurology at Washington University in St. Louis, spoke to Neurology Today about their section's plans, priorities, and progress. Their comments are edited and excerpted below.

What are some of the key problems facing this population and what should neurologists be doing to address them?

Dr. Keller: Adults with IDDs are often marginalized and face enormous health disparities. We are thrilled that the AAN has put a focus, within many constructs, on the issues about equity of care across different populations, and we want to ensure that this population is included as well in any AAN conversation about diversity and reducing health disparities. They are not getting adequate services right now. The challenge of people with IDDs from a cultural standpoint is that they are almost not thought of as equal citizens. We want to be at the table and lend them a voice. We have to speak for them from a professional standpoint as family and parent organizations have done for their loved ones. The AAN is finding its footing on these issues and we want to be there with them, reminding our colleagues that these people matter as well as the people that support them.

A lot of attention is paid to children with special needs, but when people grow up and become adults, they may not necessarily have family advocates. They may be in group home care, which has its own challenges. They may have aging family member caregivers. We and our colleagues in adult neurology have to not only understand the diseases themselves, their genetics and related care practices, but we also have to deeply appreciate the psychosocial dynamics around these individuals and their care practices, and what their own viewpoints are about their care.

How would you sum up the mission of the section?

Dr. Keller: We want to become the go-to group of providers within the AAN who will be creating best practices for training and experience for neurologists who want to provide care for adults with intellectual disabilities. We have been working in partnership with pediatric neurologists, in particular the Child Neurology Foundation and the AADMD, to lay out the basics of training required for medical school students and neurology residency pro-

grams to instill an awareness of what caring for this patient population entails. There is also a need for continuing medical education for neurologists already in practice.

What specific plans and goals do you have for advancing that mission?

Dr. Aravamuthan: We're currently attacking the problem in two ways, through advocacy and education, and ultimately a third arm of our efforts will be research.

In terms of advocacy, I'm very passionate about advocacy by publication. We have published a number of papers recently, including an article in April 2021 in *Neurology Clinical Practice* on caring for individuals with intellectual and developmental disabilities in the COVID-19 crisis which was received quite well. We also have a systematic review on the need for ongoing neurologic care for adults with cerebral palsy in *Annals of Neurology* in May.

We have also been involved in legislative advocacy. We're grateful to the AAN for letting us speak at the American Brain Coalition Congressional Neuroscience Caucus in March 2021, where we advocated for increased funding for this population. While the session was aimed at an audience of members of Congress and their staff, we have heard a lot of responses from other neurologists who tuned in and wanted to learn more about this population, which is gratifying.

You have also been involved in arts-based advocacy efforts for adults with IDD. What does that entail?

Dr. Keller: There's a stereotypic way that health care providers learn about people with specific diseases. We have all seen those black and white pictures of a person standing against a board with a black strip over their eyes for privacy, showing whatever clinical aspect of their condition the image is meant to depict. We see that in textbooks even today. It doesn't provide images of someone with one of these conditions as a person with value.

An award-winning photographer named Rick Guidotti turned his lens from fashion photography to see the beauty and differences in disability after meeting a beautiful young woman with albinism in 1997. He created a medical education initiative called *Faces Redefining the Art of Medical Education (FRAME)*, which involves short video vignettes of people with specific disabilities who speak to the camera about themselves and their lives. It's designed to teach health care providers about caring for these individuals as people, not a disease state.

Project FRAME is currently working on three new videos centered on areas we need to address in neurology. The first focuses on epilepsy in adults with IDDs. Project FRAME will be interviewing them about important issues related to their syndrome, how they view themselves and how they are treated, and what they would like doctors to know. The second is on aging and early-onset Alzheimer's in people with Down syndrome. The third is on supported decision-making and how to communicate with adults with IDDs on how decisions are made about their care. We are looking to work with the AAN to consider opportunities for Rick to share these photos and videos at an upcoming AAN Annual Meeting, to illustrate the humanity and beauty of these people.

What are you working on in terms of education?

Dr. Aravamuthan: Right now, we are developing trainee surveys to understand exactly what the gaps are in education about adults with IDDs and how we can address them. In addition, we're conducting a rigorous review of the literature aimed at identifying the gaps in our knowledge of how people with IDDs need to be cared for.

We are also developing case-based studies for practitioners of all stages who are already in the field. Another effort will involve developing a webinar series through our partner organization, the AADMD, focusing on the needs of adults with IDDs in specific domains such as epilepsy and movement disorders.

Dr. Keller: Our section now has at least 245 members, and a group of us holds monthly planning Zoom calls. We have a growing number of dedicated neurologists and pediatric neurologists who want to provide services to the people we focus on. In addition to updates and discussion of programmatic and strategic improvements, we are considering the idea of presenting member-led case studies to a broader audience of AAN members to address education needs. The IDD section overlaps with other AAN sections such as epilepsy, behavioral neurology and neurogenetics, and we would like to partner with them on educational efforts and our case studies as well.

Are there currently any programs that provide good training and/or experience for neurologists who want to provide care for adults with IDDs?

Dr. Aravamuthan: There are very few, but some members of our section have been working hard to make strides in that area. Jessica Solomon-Sanders, MD, and Julia Frueh, MD, set up a clinic for adults with IDDs while still neurology trainees at Boston Children's Hospital. That clinic has become very successful and Dr. Solomon-Sanders, who is now on the faculty at the University of Colorado, is establishing a similar program there. Joan Jasien, MD, who is trained in both pediatric neurology and medicine/pediatrics, directs the developmental disabilities program at Duke and is focused clinically and research-wise on caring for people across the lifespan. This is a very much needed, but unfortunately, uncommon approach. All of these efforts are really just starting within the past couple of years, with members of our section at the forefront.

What is your message to neurologists interested in your section?

Dr. Aravamuthan: A lot of people are called upon to care for this population in the community and don't really know about us. We want to be a home for all of those clinicians, a collegial forum where we can work together, learn together, and create models for clinical care, research, and education. We want to convey our passion for caring for these people to all neurologists and let them know that this is a population that needs us. We're an open, welcoming, collaborative section that is very goal-driven in terms of improving the lives of adults with IDDs. We are eager to work with neurologists from any field, so please come on in!

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TEENS Care About Their Care

According to a recent survey, as teenagers with disabilities mature, they become more vocal with their feelings and opinions, saying they want and need a greater voice in their own healthcare. "Adolescents Want Control of Their Healthcare" reports on the findings of the survey, in which teens with a disability indicated what they want to know in order to be participants in their care. The accompanying article, "Aid for Adolescents Who Want to Take Charge," highlights ideas about what young people need to learn to manage their care. Both articles are adapted from original pieces that appeared in the Spring 2000 issue of "Window on Wellness," a health and wellness publication for people with disabilities.

Adolescents Want Control of Their Healthcare

by Carole Iggoe

What do teens and young adults with disabilities say about their health and health care? They say they want to be in charge!

Like all adolescents, these teens also want to find out who they are, cut the apron strings, belong to their own group and be independent. In the past, parents and health care professionals often felt that they had to keep this responsibility and protect their children and patients. They focused on the disability or long-term health condition and overlooked typical adolescent life tasks that all teens need to try to master.

Today, we are changing this attitude: we are recognizing that all teens have the right to envision and plan their futures. The new Individuals with Disabilities Education Act (IDEA) legislation for transition requires that special education students be taught about the legal rights and responsibilities that all American citizens receive when they reach age 18. Among organizations that are important resources in the movement toward more independence in health management are:

- PACER Center in Minneapolis (*see Resources box next page*). For almost a decade, parents at the center have helped young people with disabilities and their families speak out for health.

- Healthy and Ready to Work (HRTW) projects. Funded by the federal Maternal and Child Health bureau, seven HRTW projects help states develop adolescent transition services that include health care. In Cincinnati, Ohio, for example, there is

Career Connections for Students at Lighthouse Youth Services. The WISH project at Shriners' Hospital serves young people in Lexington, Kentucky. For the nearest HRTW project, call the Institute for Child Health Policy at (352) 392-5904.

Teens speak out

What does "taking charge of health care" mean for teens and young adults with disabilities? In 1997, the PACER Center surveyed young people aged 14 to 25 in Minnesota. They had chronic illness or sensory, physical, learning or cognitive disabilities. Young people said they want to know:

- How to pay for their healthcare;
- More about their disability or chronic illness;
- What can happen if their condition becomes worse.
- How to make an emergency plan if their condition does get worse;

Teens want adults to talk to them about their healthcare

- They want someone to talk to about how to make their own medical decisions (less than 50 percent said they have someone to talk to).

- They want to meet someone with a similar disability who is working and living independently, who can be a mentor and guide.

- They want to be able to talk about health promotion and risk behaviors and concerns, such as:

1. Sexuality
2. Smoking

3. Alcohol and drugs
4. Feeling really angry or sad
5. Hurting oneself or being hurt by others
6. Family planning

- They want their medical providers to give them information about medical issues and their disability or chronic condition.

When Shriners' Hospitals surveyed adolescents and young adults in Florida, Kentucky, Utah, and Hawaii, the young people described two barriers to taking charge: their own fears and overprotection of their parents. For these teens, healthcare includes health skills, such as:

- Taking medications;
- Having information about specialized resources;
- Gaining self-knowledge about their maturing bodies and about their long-term conditions; and
- Gradually taking over responsibility. One participant said, "We have the same basic needs as anyone in this age group: however, we also have extra considerations and limits that may be placed on us as we work towards independence."

"For me, one of the hardest things during my teenage years was that I wanted to challenge and defy my parents, as many teenagers do. However, because I was physically dependent on them for my personal care, my desire for independence seemed thwarted. There are many other special problems you may encounter that add to the difficulty of this transitional age. For example, if your chronic illness or disability is severe, you or your parents may think it is futile to plan for the future. If your disability or chronic disease is hidden, it can seem easier to deny, hide or ignore the needs of your health."

Aids for Adolescents Who Want to Take Charge

Learn about yourself

- Find out more information about your illness or disability: talk with your parents and doctor; get books and videos; meet others with your condition.

- Find out about your body: determine what you can do for yourself; what you need help to do; get sex education.

- Figure out your strong points: try school clubs, church groups, sports, and hobbies.

- Figure out which accommodations you need to learn and work: ask therapists, special education teachers, other people with your condition, or a vocational counselor.

Take care of your health

- Learn to handle your medicine: use a medication box; contact the drugstore to fill your prescriptions; use your insurance card at the doctor's office

- Speak up for yourself: remind your parents to let you talk to the doctor; plan ahead what to say; find a way to use a record book to share your health history.

- Make medical appointments: put together a list of your doctors and therapists and their phone numbers; explain your symptoms; use a calendar for appointments; access books from PACER such as *Speak Up for Health and Workbook for Teens with Developmental Disabilities*

- Plan for adult medical services: get names and adult primary and specialty doctors; learn about health insurance and SSI (Supplemental Security Income).

Teens speak up, learn

Teens and young adults are finding their voices to speak for themselves, master their self care, even help their parents understand what they want for themselves. Teen talk groups provide a sounding board to give them insight, courage

and strategies to make these changes. Teens are surfing the Web to find out about their conditions and to meet other teens. There are chat rooms, online connections for hospital patients,

There are books for teens to help them understand their disability. There have been patient-education and self-management programs for some time for diabetes and asthma. Now self-management education extends to other conditions; for example, the book *Spinabilities: A Young Person's Guide to Spina Bifida*

Parent's role

How do teens with disabilities and chronic conditions learn to take charge of their health? Like all transitions from adolescence to adulthood, this is a process, not an event. It is a process that is best begun by parents in early childhood, but it is never too late to start. It includes teaching children about their disability and talking about puberty and sexuality.

The process should gradually grant children an active role in their healthcare, helping them learn to talk to their doctors, developing their responsibility for making appointments, and plan-

ning with them to transfer to adult medical providers.

Historically parents and providers have focused on treatment and habilitation and overlooked typical childhood development.

A life span, developmental approach helps parents support independence and loosen control. This approach emphasizes capability, experiential learning, autonomy and letting go. Parents who have had to live with health risks and other challenges their child has faced often find it difficult to allow typical adolescent risk-taking.

Here are two helpful resources for par-

ents about the developmental approach to teaching their children self-management skills in healthcare:

- A free brochure railed "Paving the Road

to a Brighter Future" (*see Resources box at end of article*).

- The chapter called "The Impact of Chronic Illness and Disability on Adolescent Development," in *Speak up for Health: A Handbook for Parents* (*see Resources*).

Physicians' Role

Physicians are key players in the process. Dr. Kathleen Charvat and Dawn Nebrig at Cincinnati Children's Hospital gave this description of the role of the physicians:

Visionary – Growing up is the goal.

Guide – Start anticipatory guidance before 12 years of age.

Teacher – Educate teens about their disability.

Coach – Build self-advocacy skills in your office.

Resource – Provide names of adult providers and discuss insurance coverage.

Cheerleader – Support families through the process.

Physicians themselves report that this is a difficult shift. It is difficult to:

- Address chronic, even life threatening health conditions with adolescent patients
- Change the role of parents.
- Address a typical developmental change like puberty, when the disability affects development.

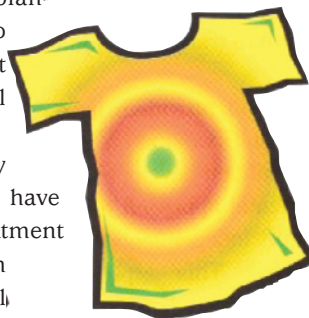
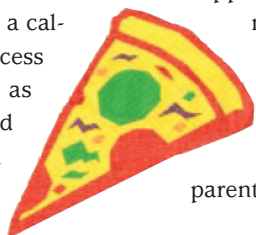
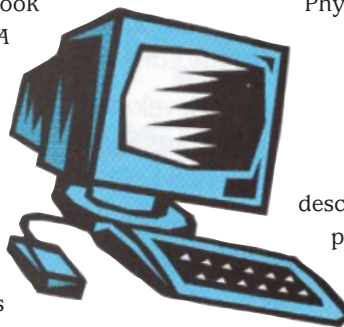
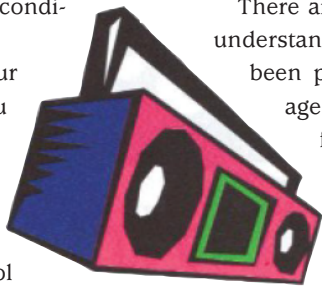
- Deal with the lack of adult providers.

It's worth it

Young adults who have achieved independence – with the support they need – say it is worth the struggle.

Nicole Robert, a young woman with muscular dystrophy, describes her achievement:

"Today I live in my own apartment. I



have an attendant who provides me with the care I need to live independently. I make my own decisions about my health-care, and I train the people who help with my healthcare treatments. With freedom comes responsibility, and like everyone else, my life has its share of challenges. However, owning my own life is worth any challenges I encounter along the way.”

This article is adapted from a brochure called “Transition to Independence,” a publication of Career Connections.

Carol Igoe is a special educator, behavioral psychologist and family support specialist in the field of developmental disabilities. Ms. Igoe is also Program Director for the Ohio Healthy and Ready to Work Project, Career Connections for Students at Lighthouse Youth Services in Cincinnati and a parent of a child with disabilities.

RESOURCES

Spinabilities: A Young Person’s Guide to Spina Bifida is available through Google Books at books.google.com/books/about/SPINabilities.html?id=VdMEAAAACAAJ

Transition to Independence is developed by the Health Care work group of the Southwest Ohio Transition Roundtable 1999, with funds from the Ohio Developmental Disabilities Council.

Visit <https://ddc.ohio.gov/Resource-Library/Publications/Transition-to-Independence>

Free copies of Transition to Independence and Paving the Road to a Brighter Future are available by calling Lighthouse Youth Services, Inc., at (513) 475-5500.

Speak Up for Health and Workbook for Teens with Developmental Disabilities can be ordered through the PACER Center:

PACER Center, Inc.

Phone: (MN only) (800) 537-2237

(nationwide) (612) 827-2966

Web site: <http://www.pacer.org>

E-mail: pacer@pacer.org



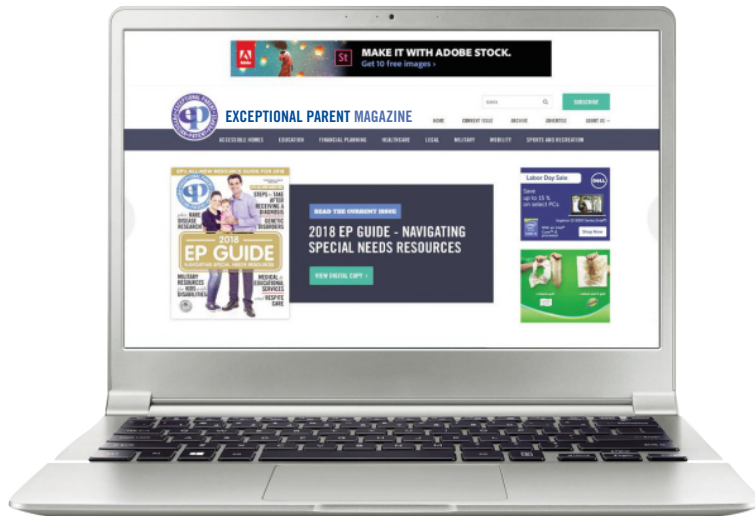
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We've introduced a range of new content to the website, including In This Issue that highlights selected content from our latest issue, and

From Our Contributors, which features the most recent offerings from regulars such as Genetic Alliance and the AADMD.

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

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EP MAGAZINE: THE JOURNAL FOR SPECIAL NEEDS FAMILIES AND PROFESSIONALS

CLINICAL SIGNS OF SLEEP-DISORDERED BREATHING IN CHILDREN WITH DISABILITIES



BY DR. AUDREY YOON, DR. LINDA PHI, DR. JOOROK PARK, DR. HEESOO OH,
DR. STEVE PERLMAN AND DR. ALLEN WONG

What is sleep-disordered breathing?

Sleep-disordered breathing (SDB) is a term used to describe a broad range of breathing difficulties or disruptions during sleep. It ranges from mouth breathing and snoring to obstructive sleep apnea (OSA) in the advanced stages, and this disruption in sleep can potentially affect the child's growth and development into adulthood.



Is sleep-disordered breathing more prevalent in children with disabilities?

Yes! In the general population, SDB has a prevalence of up to 25% in children, and OSA has a prevalence of 1-4% in children. These numbers increase significantly in children with developmental disabilities, specifically Down syndrome (Trisomy 21). The prevalence of SDB and OSA in children with Down syn-

drome increases to about 50% and 30-80%, respectively. They are highly susceptible to SDB due to their large tongue, weaker muscle tone (including neck and airway muscles), and smaller upper airway size.

Although SDB and OSA is widely discussed in Down syndrome, it is prevalent in other disabilities as well. Approximately 80% of children with Prader-Willi syndrome have OSA due to weaker muscle tone and obesity. Children with epilepsy have a higher risk of sleep apnea, and this disruption in sleep can, in turn, increase the frequency of the seizure. Research has shown that treating OSA can reduce this frequency. Infants and children with Pierre Robin

sequence are at higher risk of SDB due to a smaller lower jaw (mandible), a narrower upper jaw (palate) due to an opening of the palate at birth (cleft palate), and a tongue that is positioned farther back.

What are the signs and symptoms?

Snoring is the most common symptom of SDB in children. In addition to snoring, other signs of SDB, such as mouth breathing, sleep restlessness, sweating in sleep, dental grinding, bedwetting—and daytime symptoms such as learning problems, challenging behaviors, hyperactivity, and attention issues have been shown to

SOUND SLEEP : WHAT ARE CLINICAL SIGNS OF SLEEP-DISORDERED BREATHING?

Keeping in mind that the absence of these symptoms doesn't exclude obstructive sleep apnea, here are some symptoms to watch for:



1. MOUTH BREATHING

Large tonsils, adenoids, and turbinates in the nose were traditionally believed to be the only factors that led to mouth breathing and airway obstruction. However, they found that removing the adenoids and tonsils was not always successful in treating the mouth breathing. A more comprehensive approach evaluates not only the size of the tonsils and adenoids, but also uncovering the underlying cause of the mouth breathing. Mouth breathing can increase the inflammation seen at the tonsils and adenoids, which would result in them being bigger. These bigger tonsils and adenoids would further obstruct the airway, resulting in the child to rely even more on mouth breathing, creating this endless cycle that perpetuates the mouth breathing and inflammation. The clinical threshold for this clinical sign is the inability to breathe through the nose with lips closed for more than three minutes.



2. DIFFICULTY CLOSING LIPS TOGETHER

Another factor is difficulty in closing lips together, also known as "mentalis strain" or "lip incompetence." When trying to close their lips, a strain or dimpling is seen in the chin and the lips struggle to come together. This is a result of an underlying skeletal discrepancy in jaw development. Two scenarios can occur in which mentalis strain is seen: 1) the top jaw is located significantly more forward and the lower jaw is significantly more back, resulting in a large

"overjet" or horizontal distance between the top front teeth and the bottom front teeth (incisors); 2) long, narrow face, known as "adenoid facies" resulting from the lower jaw developing excessively downward and backwards. Being mouth breathers predisposes children to develop these long faces since they constantly have an open mouth posture. Mouth breathing can contribute to a dry mouth condition and contribute to risk for dental caries and periodontal disease.



3. NARROW PALATE

Proper development and widening of the top jaw (palate) requires normal tongue function during swallowing, breathing, and function. If your child is a mouth breather, has a low tongue posture, or is tongue tied, the top jaw becomes underdeveloped and constricted. A crossbite is often seen in the very back teeth (molars), when the top back teeth are located inside the bottom back teeth during biting. This can occur either on one side or both sides, indicating that the top jaw is narrower compared to the bottom jaw.



4. DENTAL WEAR

The exact cause of dental wear, also known as bruxism, is poorly understood. However, there appears to be an association between dental wear and SDB and other sleep disorders. It is postulated that interruptions, or constant arousals during sleep, may activate the muscles responsible for grinding, as a way to compensate for the restricted airway. The dental wear is considered a significant risk factor for SDB if the yellow, middle layer of the tooth (dentin) can be seen. Acids from gastric esophageal reflux can

also be a risk factor for dental wear/demineralization and common for those with digestive problems and sleep apnea, even in children. Prevention strategies should be considered to avoid dental caries and teeth sensitivity.



5. TONGUE TIE

Tongue tie, also known as ankyloglossia, is another factor that increases the risk of SDB. A tongue tie restricts the tongue mobility, thereby affecting the proper development of the craniofacial structures. Additionally, this restricted mobility can result in a tongue thrust, poor swallowing pattern, and/or low tongue posture. In order to determine if your child has a tongue tie, have them open their mouth and lift their tongue up as far as possible to touch the top front teeth. After, have them move it side to side. If the tongue range of motion in any of those directions is limited (less than 50%), then there is a strong possibility they have a tongue tie. Lastly, have them stick out their tongue past their bottom front teeth. If they have difficulty sticking the tongue far out, or if the tongue looks heart-shaped when extending out, then they may have a tongue tie.



6. LARGE TONSILS

Also known as tonsillar hypertrophy, large tonsils are one of the first structures that medical providers assess due to their obstruction of the upper airway. Large tonsils can be seen by having your child open his or her mouth widely. A tongue depressor can also be used to better visualize the tonsils in the back of the throat. They are considered to be large if they occupy more than 50% of the space upon opening.

be indicators for more severe sleep disturbances and sleep apnea as they grow older. It is important to note that snoring does not necessarily equate to sleep apnea and that some children do not snore loudly or at all.

How is sleep-disordered breathing or sleep apnea diagnosed?

A sleep study, also called polysomnography (PSG), is currently the gold standard to diagnose SDB and sleep apnea. However, a sleep study takes significant time, cost, and effort for the patient, and so it is not widely accessible for everyone.

It is important to find the underlying cause for SDB in order to properly find the best treatment option. The first line of treatment is typically tonsil and adenoid removal. If the tonsils and adenoids are enlarged or inflamed, the otolaryngologist (head and neck surgeon, ENT) may recommend their removal in order to reduce the obstruction in the airway. A CPAP may also be recommended, though compliance will need to be taken into consideration.

Mouth breathing can be addressed with proper diagnosis. Is your child mouth breathing due to a tongue tie? If so, then a tongue tie surgery (lingual frenectomy) may be indicated, paired with myofunctional therapy in order to increase the tongue's range of motion. Or are they having difficulty breathing through their nose (e.g., large turbinates, allergies), and therefore have to rely on breathing through their mouth? If this is the case, treating the allergy or decreasing nasal resistance is important. Orthodontists can play an important role in modifying skeletal growth by widening a narrow palate, using an appliance called an expander. This in turn increases the width of the nasal floor and nasal cavity, helps facilitate easier breathing through the nose, and decreases the need for mouth breathing.

Whatever the case may be, interdisciplinary care is recommended in order to properly address the SDB. Treatment for SDB in children is typically not solved with only one treatment modality, but an individualized treatment plan tailored to each child.

As a parent, what can you do?

As indicated above, having a sleep study for your child and working closely with an otolaryngologist is important to properly diagnose SDB and OSA. These clinical signs may put your child at risk: large tonsils, mouth breathing, difficulty in closing lips together, tongue tie, narrow palate, and dental wear. A pediatric dentist or orthodontist can help you identify these factors as well; they can help address those issues in order to reduce your child's risk of SDB and sleep apnea. We know how important sleep is for a developing child, and so we want to arm you with all the resources possible in order to improve and facilitate their overall growth and development. •

ABOUT THE AUTHORS:

Dr. Audrey Yoon is a dual-trained orthodontist and pediatric dentist. She is also a diplomat of American Board of Dental Sleep Medicine and diplomat of American Board of Orthodontics. She is an adjunct assistant professor in Orthodontics at University of Pacific, an adjunct assistant professor at Stanford University Sleep Medicine Center and also a co-director of Pediatric Dental Sleep Mini-residency program at Tufts University. Currently, her active areas of research include craniofacial growth modification, surgery-first approach of maxillomandibular advancement surgery technique, and the genomic study to identify genetic anatomical factors relating to OSA.

Dr. Linda Phi is currently a practicing orthodontist in Southern California. She is a board-certified orthodontist by the American Board of Orthodontics. She is an adjunct professor in the Orthodontics Department at the University of the Pacific (UOP), and is also an adjunct professor in the Orthodontics Department at the UCLA School of Dentistry. She received her DDS and MS in Oral Biology at UCLA, and received her Orthodontics Certificate and MSD at UOP.

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Dr. Heesoo Oh currently holds Professor and Chair of the Department of Orthodontics at the University of the Pacific, Arthur A. Dugoni School of Dentistry in San Francisco, CA. She received her DDS, MS in Pedodontics, and her Ph.D. from Chonnam National University in Kwangju, Korea. She later earned her MSD in Orthodontics at the University of the Pacific. She has received multiple awards and grants from the AAO, AAO, and NIH. Steve Perlman, DDS, MScD, DHL (Hon.) is the Global Clinical Director and founder of Special Olympics Special Smiles. Dr. Perlman has extensive experience through his private practice and his role as clinical professor of pediatric dentistry at the Boston University School of Dental Medicine. He has additional academic appointments to NYU, University Pennsylvania School of Dental Medicine, ATSU Arizona School of Dentistry and Oral Health, School of Dental Sciences University of Technology in Jamaica. Founder and past president of American Academy of Developmental Medicine and Dentistry (AADMD).

Allen Wong, DDS, EdD, DABSCD is a professor and the director of the Dugoni School of Dentistry AEGD and Hospital Dentistry program in the San Francisco area, and is the Global Clinical Advisor to the Special Olympics Special Smiles. He is current president of the American Academy of Developmental Medicine and Dentistry (AADMD) and a Fellow of the Santa Fe Group

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"My journey began as a parent, and later as a person with a disability, and has been so much richer because I simply listened, shared what I had learned along the way, recruited other advocates, and acted. Be the change you want to see in the world. Don't forget to smile!"

~ Isabel Hodge, EP 2021 Advocate Hero

CONGRATULATIONS AND THANK YOU, EP MAGAZINE ADVOCATE HEROES!

50 FOR 50



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

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

Although it's safe to say that every parent of a child with complex disabilities is indeed an advocate, many of them have also distinguished themselves in advocating in a larger arena. Many of our showcased

advocate heroes started out as parents, exceptional parents for sure. They combined their efforts in becoming teachers, therapists, counselors, lawyers, healthcare providers, researchers and activists. This special brand of advocates – along with all the others we honor – will always have a unique place in the disability movement, not only for what they have done, but also for those they have inspired.

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

ESTELLE BENSON

"Our mission is that every person affected by GBS, CIDP, or related syndromes will have access to early and accurate diagnosis, appropriate treatment, and knowledgeable support services. Our unwavering commitment to the patients we serve is built on four pillars: support, education, research and advocacy."

In 1979 Estelle Benson's late husband, Robert, came down with a bad cold and pneumonia. One week later he was in the hospital, paralyzed, and the family was given the diagnosis of Guillain-Barre Syndrome (GBS). They had no idea what it was; they couldn't even pronounce or spell it. There was no information and no one for him to speak to. They felt all alone. Ms. Benson vowed then and there, that if he ever recovered, she would do something about it.

One year later, she met with eight people who were affected by Guillain-Barre Syndrome, in her home, for a small support group. Using the leadership and organizational skills she had acquired as a teacher and a school administrator for many years, eventually, their little group began to grow. With support of people like Abbey Meyers from NORD,



STRONG FOUNDATIONS: "Our unwavering commitment to the patients we serve is built on support, education, research and advocacy."

the neuromuscular medical community, and many others who kept inspiring Ms. Benson to keep moving, she is proud to say that the GBS|CIDP Foundation now has 190 chapters in 47 countries! She said, "Through it all, we have never lost sight of why we started the foundation. That is, and will always be, putting the patient first. We vow that no one will ever be alone in this journey."

Ms. Benson "is humbled to have received many awards on behalf of the many people" their organization serves, most recently including, the 2015 President's Award from Patient Services Inc., the 2018 Honoree for the Abbey S. Meyers Leadership Award from the National Organization for Rare Disorders, and the 2020 Public Recognition Award from both the Peripheral Nerve Society

(PNS) and the American Association of Neuromuscular & Electrodiagnostic Medicine (AANEM).

Even though Ms. Benson has technically retired, she is still very involved with the Foundation, and doubts that will ever change. She said that she is "very proud of my family, two children, four grandchildren and I have recently become a great grandmother."

ROBERTA CARLIN, MS, MA, JD

"Advocacy is a two-tier responsibility for everyone, which includes systems change and individual advocacy. Always remembering the important guiding light, 'nothing about us without us' reminds me daily of the need to have a strong and consistent voice to right the wrongs in society and advocate for an inclusive and accessible world."



GUIDING LIGHT: *"Nothing about us without us" reminds me daily of the need to have a strong and consistent voice to right the wrongs in society and advocate for an inclusive and accessible world."*

Roberta Carlin has been the Executive Director of the American Association on Health and Disability (AAHD) since 2002. AAHD is dedicated to ensuring health equity and inclusion for persons with disabilities through policy, research, education and dissemination. Ms. Carlin became involved in the disability and health field 35 years ago as a result of growing up with two cousins with intellectual disabilities and watching the challenges encountered by family members, as well as the ongoing need for both systems and individual advocacy. She has a long-standing commitment and history of working to eliminate health disparities and advocate for health equity, inclusion and full accessibility, and promote health and wellness initiatives in children and adults with disabilities.

Ms. Carlin's work at AAHD includes the launching of the Medline indexed Disability and Health Journal, the creation of the AAHD Research, Knowledge Translation and Dissemination Center, the NIDILRR funded Health Insurance Literacy Academy, and the National Disability Navigator Resource Collaborative. She is proud of AAHD's outreach and engagement

MARC P. DIFAZIO, MD

"My career working with individuals with neurologic special needs has been incredibly rewarding. Children and adults who have such challenges have always demonstrated to me resiliency and strength, sometimes in the face of remarkably physical and intellectual difficulties. Their parents have likewise been an amazing example of how to nurture children to achieve the highest level of accomplishment. I am so appreciative for the opportunity to share in the care of these families!"

Marc DiFazio, M.D., is the Vice President of Ambulatory Services at Children's National Hospital. He completed his pediatric and neurology training at Walter Reed Army Medical Center, and went on

to become the Chief of Child Neurology at Walter Reed, where he served on active duty until 2005 before transitioning to private practice in Rockville, MD, delivering subspecialty care to patients in their community. The experience established a solid understanding of care delivery to special needs children in their community, and the unique challenges experienced by this population.

Dr. DiFazio "is well-known in the metropolitan area pediatric community for his service, leadership and expertise in clinical child neurology, with interests and concen-



LEADING THE WAY: *"Children and adults who have neurologic special needs have always demonstrated resiliency and strength, sometimes in the face of remarkably physical and intellectual difficulties."*

tration in the areas of Tourette syndrome, headache/migraine, concussion, behavioral neurology/autism and the use of botulinum toxin and intrathecal baclofen in a variety of conditions. Dr. DiFazio has focused on the treatment of Cerebral Palsy and hypertonias with botulinum toxin and ITB throughout his career. He continues to serve in the Army Reserves as the Command Surgeon of US Army Reserve Legal Command. His leader-

ship roles include service as: President, Medical Staff, Children's National Hospital, 2018-2020; Executive Director, Children's National Physicians and Associates (CNPA) 2021-Present; Vice President, Ambulatory Services, Children's National Hospital; Medical Director, Ambulatory Neurology, CNH 2017-2021; Co-Chair, Children's National Medical Executive IT Subcommittee, 2019-

2020 Chair, Credentials Committee, CNH 2020-Present.

Dr DiFazio attended the Stritch School of Medicine Loyola University Maywood, Illinois receiving a Medical Doctorate; Pediatrics, (Residency) at Walter Reed Army Medical Center Washington, D.C.; Neurology with subspecialty Qualification in Child Neurology, 1996-1999 (Second Residency) at Walter Reed Army Medical Center Washington, D.C.; and is currently pursuing his Healthcare Master of Business Administration at George Washington University Washington, D.C.

involvement with NIH All of Us Research Program, which focuses on advancing individualized health care to all Americans. She has overseen AAHD's advocacy and research initiatives resulting from COVID-19 and its impact on people with disabilities, as well as AAHD's women's health initiatives.

Ms. Carlin serves on numerous coalitions and task forces and previously chaired the Friends of NCBDDD, served on the Executive Committee of the APHA Disability Section, the HHS National Biodefense Science Board,

and as a Commissioner on the Montgomery County Commission for People with Disabilities. Prior to AAHD, she was the Associate Executive Director/Director of Government Affairs at the Spina Bifida Association of America. Earlier in her career she was a Certified Rehabilitation Counselor. She has a Juris Doctorate (JD) degree, a MS in Rehabilitation Administration and a MA in Counseling and Guidance. She resides in the MD suburbs with her husband, and they are proud parents of three adult children and grandparents of seven.

THOMAS RICHARD (TOM) HARKIN

"Growing up with my brother Frank, who was totally deaf, I saw how societal barriers and attitudinal barriers restricted him in so many ways: education, employment, travel, and just in everyday living. Frank was my first inspiration to engage in the efforts to address this discrimination against persons with disabilities. Later, during my early years in the US House and Senate, I was continually inspired by so many in the disability rights movement, individuals you will see in the documentary film 'Crip Camp'. They engaged in nonviolent protests and demonstrations across America... The most memorable demonstration occurred when a number of individuals fell out of their wheelchairs and crawled up the steps to the US Capitol to show that was the only way they could enter. This became known as the 'capital crawl'. All of these brought to the attention of the American people the discriminations faced by persons with disabilities. In 1989 I became the lead sponsor in the Senate of the bill which would become the Americans with Disabilities Act (ADA), signed into law July 26, 1990. This law has changed the face of America to be more inclusive and barrier free for all persons with disabilities. I was so privileged and honored to be in the right place at the right time to be able to lead this bill through the legislative process and to the President's desk.

Many times, I read that I was the 'author' of the ADA. While I did have a hand in drafting it and getting it passed into law, the real 'authors' of the ADA are the disability rights pioneers who labored for over 20 years to get this law enacted. I was, and still am, so proud of all these pioneers who would not take 'stay in your place' as an answer to the barriers to full inclusion for all persons with disabilities."

In 1974, Tom Harkin was elected to Congress from Iowa's Fifth

Congressional District. In 1984, after serving 10 years in the U.S. House of Representatives, Senator Harkin challenged an incumbent senator and won. Iowans returned him to the Senate in 1990, 1996, 2002, and 2008. He retired from the United States Senate in January 2015.

As a young senator, Senator Harkin was tapped to craft legislation to protect the civil rights of millions of Americans with physical and mental disabilities. What emerged from that process would later become his signature leg-



PIONEER SPIRIT: "I was, and still am, so proud of all these pioneers who would not take 'stay in your place.'"

islative achievement – The Americans with Disabilities Act (ADA). The ADA has become known as the "Emancipation Proclamation for people with disabilities."

To preserve the intent of the ADA after several court rulings weakened its standards, Senator Harkin and Senator Orrin Hatch (R-UT) introduced the ADA Amendments bill to ensure continuing protections from discrimination for all Americans with disabilities. It was signed into law in September 2008. For his ongoing and dedicated work to people with disabilities around the world, Senator Harkin was twice nominated for the Nobel Peace Prize. In September 2009, Senator Harkin became chairman of the Senate Health, Education, Labor and Pensions (HELP) Committee.

Senator Harkin was born in Cumming, Iowa, the son of an Iowa coal miner father and a Slovenian immigrant mother. To this day, he still lives in the house in Cumming where he was born. In 1968, he married Ruth Raduenz, the daughter of a farmer and a school teacher from Minnesota. They have two daughters, Amy and Jenny, and four grandchildren.

ISABEL HODGE

"One of the biggest compliments I received was from an attorney many years ago who said, 'Isabel Hodge is like a bulldog who bites at heels until she gets what she wants and smiles while doing it.' I never gave up. I keep a list.

I have met with parents and advocates with disabilities living in countries who do not have a civil rights law like the ADA or reliable social protection systems.

They are eager to see progress and learn from the US example. Listen to their life stories and figure out what you can do to help, big or small, and add it to your list. It is common occurrence for parents and advocates from all over the world to stay at our house and share their stories over dinner. Each visitor has their name engraved on a wooden center piece on our dining table. It's quite full now but our door is still open.



SMILING THROUGH: "I simply listened, shared what I had learned along the way, recruited other advocates, and acted."

My journey began as a parent, and later as a person with a disability, and has been so much richer because I simply listened, shared what I had learned along the way, recruited other advocates, and acted. Be the change you want to see in the world. Don't forget to smile!"

Isabel Hodge is a distinguished leader and advocate in the international disability rights movement. As Executive Director of the United States International Council on Disabilities (USICD), she manages a 30-year global networking and consulting hub with relationships with organizations of persons with disabilities in countries around the world. Isabel's advocacy work involves striving for the US' ratification of and promoting and assisting countries with their implementation of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). She is guid-

ed by a commitment to the full and equal enjoyment of all human rights and fundamental freedoms by people with disabilities.

Ms. Hodge is a native of Glasgow, Scotland and a US Marine Corps veteran. Prior to joining USICD, she was a Senior Analyst for the US Department of Defense Office of Special Needs. She was also an Exceptional Family Member Program (EFMP) specialist at Headquarters Marine Corps and an installation EFMP program manager. In 2000, she received the Commander-in-Chief's Special Recognition for Installation Excellence Award from President Bill Clinton. Ms. Hodge currently serves as the Vice President of Disabled Peoples International North America and the Caribbean and on the Board of Directors for Wheelchairs for Kids International. She is an advisor to the Enabled Children's Initiative, which is a non-profit working to improve the quality of life for Afghans with disabilities.

Her middle child, Allistair, is an adult who has autism and an intellectual disability. Ms. Hodge is also a person with a disability and is the spouse of a disabled Marine Corps veteran.

MATTHEW HOLDER, MD, MBA

"I have been lucky enough to watch and learn from some of the most magnificent self-advocates, family-advocates, and professional-advocates in the field. In my opinion, these are some of the very best people that humanity has to offer. If you want to see true strength of will and strength of character, you will find it here. Over the years, those advocates have taught me that advocacy means never giving up – to be told 'no, it can't be done' 1000 times, and to still be there for the 1001st time, when you are finally able to make it happen. It means being a lion when you need to be a lion, and it means walking away when you have lost, only because you already have a better plan to win."



CHARACTER COUNTS: "Self-advocates, family-advocates, and professional-advocates are some of the very best people that humanity has to offer. If you want to see true strength of will and strength of character, you will find it here."

Dr. Matthew Holder earned his BA in psychology, MBA with a focus on entrepreneurship and MD degrees from the University of Louisville. He helped co-found the American Academy of Developmental Medicine and Dentistry (AADMD) in 2002 and served as that organization's Executive Director and, later, President, and is still active as a Board member. In 2009, as part of his AADMD work, he founded the National Curriculum Initiative in Developmental Medicine – a national effort to standardize the emerging field of Developmental Medicine – the care of adults with IDD. This work led to curriculum changes in over 30 medical schools, nurse practitioner schools and residency programs. Additionally, Dr. Holder founded the American Board of Developmental Medicine to certify physicians in the field of Developmental Medicine.

In 2005 Dr. Holder became the Global Medical Advisor for Special Olympics, creating the MedFest program and developing the first set of IDD-specific physical examinations protocols for that program. He later served as the Chair of the Medical Advisory Committee until retiring from that post in 2021. During his time at Special Olympics Dr. Holder trained tens of thousands of medical students and practicing physicians and the physical protocols that he and his team developed improved the quality of sports physical performed on millions of athletes with intellectual disabilities in over 170 countries.

In 2014, Dr. Holder cofounded the Lee Specialty Clinic in Louisville, KY. The Lee Specialty Clinic is considered the preeminent model for interdisciplinary outpatient care for

patients with IDD. Funded by the Kentucky Cabinet for Health and Family Services Department of Behavioral Health and Intellectual and Developmental Disabilities, the clinic is home to 18 different teaching programs, including the only dental residency training program in the United States with a 100% IDD patient base. As a pioneer in the field of developmental medicine, Dr. Holder has met with multiple Presidents, congressional representatives, Surgeons General, and other national and state leaders with the message of systemic change in the way we provide healthcare to the IDD population. Examining both the clinical and the business side of medicine, Dr. Holder firmly believes that there is a better way to provide healthcare services to this population that will produce far better outcomes at less cost. In the near future, he will be leading the charge in a newly formed organization to prove it.

SETH M. KELLER, MD

"I am an advocate for people with intellectual and developmental disabilities by my ability to share my expertise, personal stories, and by my leadership and networking skills. The end of the day for my efforts will be if I am able to help those with IDD, their families and supports, and we all benefit from the experience and knowledge of our combined energies and dedication."

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. 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. Dr. Keller is the Past President of the American Academy of Developmental Medicine and Dentistry (AADMD). He is the co-president of the National Task Group on Intellectual Disabilities and Dementia Practices (NTG). He is also the chair of the Adult IDD Section with the American Academy of Neurology.



NEUROLOGIC NETWORKING: "We all benefit from the experience and knowledge of our combined energies and dedication."

Dr. Keller is actively involved in national and international I/DD health education as a speaker and webinar and workshop participant. He is a co-author on a number of articles and book chapters relating to aging and dementia in those with IDD.

Raised in Philadelphia, PA, Keller received his bachelor's degree from Temple University, earned his medical degree from The George Washington University School of Medicine in 1989, and completed his neurology internship and residency at Bethesda Naval Hospital. He also served as a neurologist at the U.S. Naval Hospital in Okinawa, Japan.

SHARON LEWIS

"Advocacy starts at home. Families of children with disabilities are critical in raising strong adults who will live self-determined lives and contribute to our communities. Parents do this by holding both our systems and our kids to high expectations, allowing them to take risks and make mistakes, rejecting segregation in the name of safety, teaching our children to advocate for a just and equitable world – and by getting out of the way when our youth become young adults who need our support, not our paternalism."

Sharon Lewis is a national expert in disability policy who currently assists publicly-funded health and human services programs as a consultant. As a parent to three amazing adult daughters, one who experiences intellectual and developmental disabilities (I/DD), she has spent the past twenty-five years advocating for equitable and inclusive communities for all, and for the rights of, and opportunities for, people with disabilities.

Ms. Lewis was appointed by President Obama to multiple leadership roles at the U.S. Department of Health and Human Services (HHS) including Principal Deputy Administrator of the Administration for Community Living (ACL), Senior Disability Policy Advisor to the HHS Secretary, and Commissioner of the Administration on Intellectual and Developmental Disabilities, after serving on President Obama's transition team for the U.S. Department of Education. At HHS,

she co-founded ACL, established initiatives to improve I/DD employment outcomes, expanded alternatives to guardianship, furthered higher education opportunities for people with I/DD, promoted Olmstead implementation, and advocated for the human and civil rights of people with disabilities and their families. In collaboration with CMS leadership, she also worked on significant reforms in Medicaid home and community-based services (HCBS), known as the "HCBS Settings Rule," requiring community integration and person-centered services.

In her time as Congressional committee staff, Ms. Lewis provided critical leadership in the passage of disability-related amendments to laws including the Head Start Act, the Higher Education Act, the American Recovery and Reinvestment Act, and the Americans with Disabilities Act, as well as the Affordable Care Act. She led the drafting and House passage of the first federal bill seeking to eliminate restraint and seclusion in schools, and to maintain accountability for students with disabilities in federal education policy. Prior to her federal service, Sharon led public policy, legislative strategy and grassroots organizing for multiple I/DD non-profit advocacy organizations and coalitions in Oregon.

Ms. Lewis is the recipient of numerous honors, including the Consortium for Citizens with Disabilities Chairman's Award, a Joseph P. Kennedy, Jr. Foundation Public Policy Fellowship, and multiple advocacy leadership awards from the disability community. She is a graduate of Washington University in St. Louis.



GREAT EXPECTATIONS "We do this by getting out of the way when our youth become young adults who need our support, not our paternalism"

HAROLD (HACKIE) REITMAN, MD

"To me, advocating for those of us whose brains and bodies are different has meant the opportunity to fight for the underdog. It has meant taking positive actions to encourage all the families, friends, and self-advocates to support each other in maximizing our potential, while emulating such heroes and mentors as Dr Rick Rader and Dr Steve Perlman in uniting silos of research and advocacy. Society needs to understand and embrace neurodiversity and all of our differences for the benefit of ALL of us."

Harold "Hackie" Reitman, M.D. is the founder of the nonprofit Different Brains® Inc. and DifferentBrains.org. He is also an author, filmmaker, retired orthopedic surgeon, former professional heavyweight boxer, the past chairman and president (and current board member) of The Boys and Girls Clubs of Broward County, and a neurodiversity advocate. However, it was his role as a father that led to his dedication to speaking out for the differences in our brains.

Hackie's daughter Rebecca grew up with epilepsy, 23 vascular brain tumors, and underwent two brain surgeries before the

age of five. Her struggles and recovery put him on the road to, through 26 professional heavyweight boxing matches, raising awareness and money for children's charities (to which he donated every fight purse). Rebecca eventually went on to graduate from Georgia Tech with a degree in Discrete Mathematics, and Dr. Reitman wrote and produced a film based on her experiences there. After graduation, Rebecca received a diagnosis of Asperger's syndrome. Hackie, shocked at his own ignorance of the topic despite being an M.D., embarked on years of research that culminated with his book *Aspertools: The Practical Guide for Understanding and Embracing Asperger's, Autism Spectrum Disorders, and Neurodiversity*.

This experience revealed to Hackie the

interconnectedness of the conditions that fall under the neurodiversity umbrella, while alerting him to the in-fighting and fractured relations that often plague the organizations

tasked with serving the community. Convinced that overcoming these schisms could help all of society, Hackie forged the Different Brains philosophy of inclusive advocacy: "Supporting Neurodiversity - From Autism to Alzheimer's and All Brains In Between".

Hackie is the main mentor of the neurodiverse participants of the Different Brains Mentorship Program, the host of the weekly inter-

view show *Exploring Different Brains*, writes blogs for the DifferentBrains.org, and tours the country speaking at conferences, conventions and private functions, all with the goal of improving the lives of neurodiverse individuals and their families, and maximizing the potential of those with different brains.



THE GOOD FIGHT: "Advocating for those of us whose brains and bodies are different has meant the opportunity to fight for the underdog."

NEIL ROMANO

"The Declaration of Independence says: 'We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty and the pursuit of Happiness.' Being an advocate for the rights of people with special needs gives me the great honor of helping to make that simple truth more of a reality in the lives of millions of Americans."



INDEPENDENT THINKER: "Being an advocate for the rights of people with special needs gives me the great honor of helping to make that simple truth more of a reality in the lives of millions of Americans."

In 2007, Neil Romano was nominated by President George W. Bush to be the Assistant Secretary of Labor for Disability Employment Policy and was unanimously confirmed by the U.S. Senate. During his time as Assistant Secretary for ODEP, he developed a series of outreach programs to help Americans in general and businesses in particular, understand the great value of people with disabilities in the workplace. Called "A conversation with America" his goal for this program was to accentuate the positive nature of people with disabilities and combat negative stereotype of people with disabilities in our society.

He has also served as a member of the President's Committee for People with Intellectual Disabilities, The United States Access Board and The Committee for Purchase from People Who Are Blind or Severely Disabled. In 2015, he was selected to be a member of the National Council on Disabilities for a term of three years. In 2018, he was reappointed by Senator McConnell to another three-year term on NCD and was elevated to the council's Chairmanship by President Trump. During his time as Chairman, NCD released a series of groundbreaking reports that called for an

end to the Ability One program and the use of section 14C of the Fair Labor Standards Act, which allows employers to pay people with disability less than minimum wage. Under Mr. Romano's leadership NCD released a series of bio-ethic reports, which demonstrated the poor treatment, by sectors of the medical community, of people with disabilities. These bio-ethic reports proved to be invaluable in the fight against the discrimination against people with disabilities during the covid-19 pandemic. He still serves on NCD.

Recently Mr. Romano has become involved with a significant effort to help people with dis-

abilities understand and receive their full benefits under Medicare and he is working launching the largest private disability employment program in the history of the United States. He is published in various academic journals on subjects ranging from drug abuse to disability issues.

Born with dyslexia, in 2013, Neil was diagnosed with leukemia. Born in Brooklyn, New York in 1954, Mr. Romano presently lives in Florida with his wonderful wife of 32 years, Barbara. They have two adult daughters, Mrs. Bianca Romano-Stephens, a physiotherapist in Texas and Christina Romano a practicing attorney in Kentucky.

JOSEPH VALENZANO, MBA, CMA, CPA

"Someone once said that we would become a better people when we learn to regard people with disabilities as people to be respected, not as problems to be confronted. In the years that I served as CEO of Exceptional Parent, that was a driving force in all that we did, the programs we created, the voice we gave to parents and the witness we served to attest to the remarkable accomplishments that Exceptional Parents and caregivers have achieved. We have been so privileged to serve them."

Joseph M. Valenzano was President & CEO of EP Global Communications, Inc. and *Exceptional Parent Magazine* from the mid-1990s through 2016. Under his leadership, EPGL worked with the Department of Defense on issues concerning returning veterans with significant disabilities, including TBI and PTSD. EPGL developed dozens of online educational seminars for physicians and allied health care professionals, and also made these accessible to families. He helped create the World Congress & Exposition on Disabilities, bringing together education and exhibitions of technology and medical equipment from around the world. He also was instrumental in developing and implementing Disability Awareness Nights, with Major League Baseball clubs, honoring top advocates across the country.

Mr. Valenzano is the recipient of several honors and awards from the disability com-

munity, including those from the Arc of Massachusetts, the Colleen Giblin Foundation, and the Arc of New Jersey. He received the Theresa Award, and the 2005 Distinguished Service Award for work on behalf of people

with Fragile X. He is past Chair of the Executive Advisory Board to the Child Neurology Foundation, and past Chair of the Executive Advisory Board to the American Academy of Developmental Medicine and Dentistry.

Believing in giving back to the community, Mr.

Valenzano has been an educator since 1972. He has taught business, finance, and publishing courses at various universities, including: Northwestern, Kean, as well as Bergen Community

College; Passaic County Community College, Ocean County Community College and Atlantic Cape Community College, NYU's Graduate School of Business, and NYU Gallatin School's Advanced Publishing program. He also held various senior executive positions with communications companies, such as The Thomson Corporation and McGraw Hill, Inc. He received has an MBA in Finance from Fairleigh Dickinson University, has an Advanced Professional Certificate in Accounting (APC), and is a Certified Management Accountant (CMA).

A native New Yorker, Mr. Valenzano has been married for 50 years to Patricia Valenzano and is the father of five boys and grandfather of 10 grandchildren.



EXCEPTIONAL LEGACY: "We become a better people when we learn to regard people with disabilities as people to be respected, not as problems to be confronted."

SHERYL WHITE-SCOTT, MD, FACP

"The last year has made crystal clear the need to address health disparities for people with disabilities. I am thankful that over the last 34 years, I have been able to assist by providing medical services. I continue to advocate for people with disabilities as we all fight for health equity."

Sheryl White-Scott MD, FACP, is a Medical Consultant for the Medically Frail residential program at AHRC/New York City and Medical Specialist for the Metro Developmental Disabilities Services in New York, New York. AHRC/New York City is a not for profit, family governed organization, dedicated to enhancing the lives of individuals with intellectual and developmental disabilities and their families. The Metro Developmental Disabilities Services Office of the New York State Office for People with Developmental Disabilities is the state government office responsible for helping people with developmental disabilities live richer and healthier lives in Manhattan and The Bronx.

Dr. White-Scott specializes in clinical services for adults with developmental disabilities. She has worked extensively with this population and has a special interest in health care delivery for women with developmental disabilities and individuals with developmental disabilities from minority populations. She has done numerous presentations on primary health care, prevention, aging, women's health and training medical professionals in the delivery of health services for individuals with developmental disabilities. The clinical response to



BUILDING BRIDGES: "I continue to advocate for people with disabilities as we all fight for health equity"

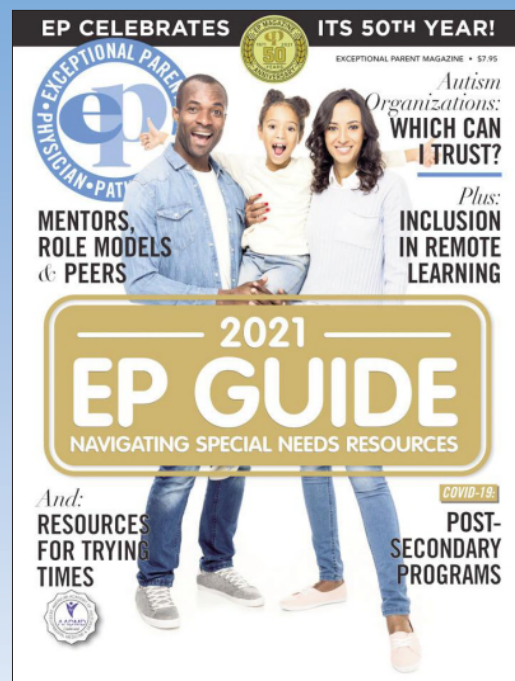
the COVID-19 pandemic has become a new area of expertise for her, as for many clinicians, working through this challenging time. Dr. White-Scott resides in New York City with her husband and two daughters. •



EP MAGAZINE CELEBRATES 50 YEARS AS AN INDISPENSABLE RESOURCE FOR THE DISABILITY COMMUNITY

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

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PREPAREDNESS, THE ESCALATOR, AND YOU

BY LAURA GEORGE, EMDL

How do you help a person in a wheelchair go up an escalator? For those of you reading this, the answer is obvious. Yet, it was actually a question I had to ask at a shopping mall years ago. The topic of emergency preparedness is much like an escalator. There are processes, safety concerns, and appreciation for its creation.

Yet, emergency preparedness for persons of all ages and types is much like this escalator question. The question will remain unchanged, regardless of the season, although our approach to it may need to be forever evolving.

When I first brought up the topic of emergency preparedness, back in 2006 at a hospital discharge planning for my husband new to paralysis, the team had no answers for hurricane preparation. I was told to abandon my spouse because he was disabled while we

A WAYS TO GO: "While emergency preparedness may not yet be 100% accommodating of everyone with a disability, I still remain hopeful that emergency preparedness and response will continue to evolve in a positive direction."



were expecting our first child. Then, politicians, non-profits, medical professionals, neighbors, and more were called, in the hopes of receiving a better answer. No matter who I called, the answers were always the same: “We don’t have time for him;” “We have no room for him;” “In a disaster, people like him take time from others who really need assistance;” and more. It hurt so deeply to know that society could be so mean, especially having been brought up with the concept that all life is created equal and worthy.

The hurt turned into anger (*Never mess with a pregnant mother!*), and I wondered what I could do to change those thoughts. The first call went to a well-known spinal cord support organization where I asked them what they were doing to address the topic that I could offer support for. Of course, I had to tell them my story.

“But you are in Florida! How can you tell this story?”

“I know. I am embarrassed. What did I do that was wrong?”

I quickly learned that I did not do anything wrong. Instead, I learned we were subject to indifference, ignorance, and lack of education, all because my husband was paralyzed.

Very quickly, I realized it was important to find the words to raise awareness, and I did that by attending any meeting I could find in my community addressing the topic and asking questions.

- **What are your plans for people in wheelchairs who have pregnant spouses and need to seek shelter?**

The people in wheelchairs take too long to take care of and they must be left at home.

- **What assistance do you have for people in wheelchairs at the shelter?**

We have limited assistance, and their caregivers are not allowed to come with them. No, we don’t help them into their cots.

- **How long does the registration process for your “special needs” shelters take?**

Six months. That bypasses an entire hurricane season.

- **What do we do for the current season until formally registered?**

Get prepared, like everyone else does.

**“Understand,
at the end of
the day, we are
all humans, and
in a disaster,
we all should be
treated equally
as worthy of
living.”**

Not letting my anger get the better of me, I changed course and realized that if this was happening to my family, there were many more out there. Advocacy would become important. Meetings became a podium to voice my questions and concerns publicly. Attending the community emergency preparedness meetings, and political forums, would present important opportunities to voice questions and learn that the responses would be met with glares, stares, and fears.

For the next several years, I met with local, county, state, regional and national organizations on both sides of the discussion, especially with first responders and representatives of the disability community. At the same time, stories were piling up and being collected that were as alarming as my own:

- An adult member of the autism community was told to take shelter with a can opener. After the storm and three days later of not eating, it was learned that they were not told specifically to use a manual can opener.
- A 17-year-old girl with pulmonary arterial hypertension, and always needs an oxygen tank, was shorted her regular delivery supply and spent the storm with her panicked parent watching

over every bit of supply was used slowly until the company could resume deliveries and fix the situation.

- In order to gain shelter during a hurricane, a quadriplegic would put on his winter coat, get into his van, close the windows, turn on the heat and wait until his temperature was 104 degrees. Then, he would drive himself to the hospital and ask to be admitted for his high temperature.
- An experienced sign language interpreter found himself as intermediary between the county emergency management who did not feel there was anyone in a home destroyed from a tornado (due to no response from door knocking) and a family with parents who were deaf who lived in the home (found in the home moments later). Had the interpreter not been there, the children who could speak and hear would have had to interpret the news of their uncle’s death in the tornado to their mother who was their uncle’s sister.

- Countless lives were lost in many disasters when people with disabilities who were living independently on their own were sent to nursing homes, never to regain their independence again.

My questions to the emergency design planners became more expansive. Why? That word became a favorite question or tool. As I attended more meetings and became better known, people started to approach me on a regular basis, thanking me for asking the questions I posed that raised their awareness levels. In drills, I was thanked for participating and inserting injects. An inject is exactly that; a situation that is, with or

without warning, inserted into the drill for the role players to address and solve during the drill. Those were always intriguing and no one ever knew what I would come up with. A simple example: at a shelter, an adult who is paralyzed in a wheelchair has come in without their caregiver at the last minute. The adult can be transferred to the cot with light assistance, and the shelter has the cot at the appropriate height. But the paralyzed individual is legally blind and has a decubitus (bedsore) wound. The role players in the drill would have to figure out how to accommodate the person on both situations.

As time progressed, there were various conferences to attend and, after a short time, preparedness for persons with disabilities would start to appear on the agenda. Those first presentations would start with the basics of water, food, flashlight, batteries, and can openers. I would not dare suggest that I was the originator of the idea, but after I sat in on several sessions asking some really tough questions, those same sessions would now include such topics as dialysis, dementia, and making sure that the service dog followed with the person, as opposed to being left behind. Preparedness classes would start to become accessible and inclusive, allowing for people with disabilities to also participate and help others after disasters. Established organizations such as the Federal Emergency Management Agency (FEMA) and some local chapters of the Community Emergency Response Team (CERT) would design some creative methods to be inclusive—through technology by including American Sign Language (ASL) in their classes, or by having the group led by a professional who has experience in working with people with autism and teaching them how to be a part of a CERT team. Even county emergency fairs would change to include ven-

READINESS REPORT : GOALS ON THE HORIZON

With knowledge of the progress made so far, this writer passionately hopes for continued inclusiveness in emergency preparedness education, planning and response. The following is just a brief wish list for the future:

- *The topic of emergency preparedness and response would be first raised at the hospital upon discharge, where many disabilities are first diagnosed.*
- *People who are deaf/hard of hearing would have unrestricted access to information on upcoming or immediate weather, man-made, chemical, biohazard, or environmental situations.*
- *In all emergency operation centers, people who have disabilities would work side by side with emergency management to successfully help them help anyone they would encounter with a disability.*
- *In all forms of security, officers (regardless of rank) would learn how to successfully and calmly work with people who have PTSD, autism, or other mental health concerns.*
- *A better mask design would be developed, so that we can see each other's faces to access the verbal and emotional aspects of communication that we so badly need to get along.*
- *Shelters and hospitals would never separate the last trimester pregnant mother from the husband pre-, during, and post-disaster.*
- *Accommodation of rare disorders during a disaster, would not be dismissed and instead be included in planning.*
- *All neighborhoods would have a complete, inclusive community-preparedness committee where they can address the challenges, first hand, that are faced in their own neighborhoods. (An example of this might be a home owner association.)*
- *Properly-documented service dogs would be accepted as workers with their persons, without question, during a disaster.*
- *All websites and social media relating to pre-, during, post-preparedness, would be completely accessible for those with blindness/low vision issues, as well as those who are deaf/hard of hearing.*



dors that would address the needs of the elderly, children, indigent, second language communities, and the disabled, in terms of disaster preparation.

Requests for presentations started to include more challenging questions from the host organizers, such as addressing the culture and communication of those with disabilities. Through meetings, it would be learned that shelters were receiving technology, supplies and cots that would assist people with disabilities and others. More ASL interpreters would be seen during community-news leader weather briefs. Educational materials on preparedness would be printed in multiple foreign languages, including Braille.

Police and other first responders were now asking for, and being trained in appropriate response skills when working with those with autism, developmental disabilities, and post-traumatic stress disorder (PTSD). Additional shelters were now being designed to keep the elderly with their dogs, for comfort to ease anxiety. For people with low incomes, at times of disaster, vouchers are used to augment their lost income and replace items. This in turn creates the opportunity to return to work faster and regain financial independence. As seen with COVID-19 and other infections such as MRSA, SARS, and sepsis, a wider variety of accessible resources are being issued in different formats to ensure quick distribution of medical information.

Community disaster planning committees are now starting to reach out to Independent Living Centers and homeless shelters to include their expertise in accommodating their consumers in disaster planning. Special diets (hypoglycemic, diabetics, celiac, immune compromised) and sensory processing disorders (lights, noise, activity levels) are just now being added into emergency preparedness planning. Let us not also forget the creation of laws waiting to be voted and approved on such as REAAD (Real Emergency Access for Aging and Disability Inclusion for Disasters Act), which ensures a stronger voice for emergency planning people with disabilities and DRMA (Disaster Relief Medicaid Act), which would ensure access to Medicaid during a disaster.

So, to answer the question of, "How do you help a person in a wheelchair go up an escalator?" You cannot. Instead, you can help by guiding them to the elevator, so they can reach the top independently. While emergency preparedness may not yet be 100% accommodating of everyone with a disability, I still remain hopeful that emergency preparedness and response will continue to evolve in a positive direction. Who knows? Maybe one day you, the reader, will be telling me about the successful improvement to emergency planning that you brought about. •

If you or someone you know wants to get more involved, they can reach out to FEMA, NCIL, Partnership for Inclusive Disaster Strategies (PIDS). Get involved!

ABOUT THE AUTHOR:

Laura George, EMDL (Emergency Management Disability Liaison) has a long history of providing education and advocacy towards the improvement of emergency preparedness planning of people with disabilities. In addition to being a presenter, she also authored *Emergency Preparedness Plan: A Workbook for Caregivers, People with Disabilities, the Elderly and Others*. She received her Bachelor's Degree from Nova Southeastern University, and has assisted in many disasters for the past several years, and has received many awards and accolades for her work. Her spare time is spent with her daughter (PANS/MCS) and dog. For more information, you can find her website at www.laurageorgeemdl.com



FROM OUR FAMILIES... TO YOUR FAMILIES

MILITARY SECTION

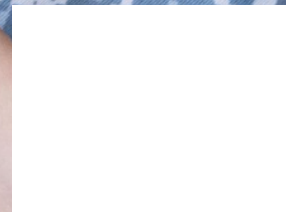
MILITARY LIFE

60 HELPING YOUR CHILDREN CHANGE SCHOOLS

PUZZLES AND CAMO

62 LESSONS FROM THE SHORE

By Shelly Huhtanen





Frequent moves to new duty stations is a fact of military life, and your child will be asked to respond to the routines and demands of military life as well.

Being prepared to help your school-age children change schools can go a long way to helping them adjust to their new environment in healthy ways. Parent preparation can mean a smooth school move for your children from one school system to the next.

When making moves within the continental United States, the Interstate Compact on Educational Opportunity for Military Children addresses educational transition issues of military families. Adopted by all states and the District of Columbia, the Interstate Compact replaces varying individual state education policies that affect transitioning military dependent children and supports uniform treatment for these students as they transfer between school districts and states. The Interstate Compact covers all schools, including Department of Defense Education Activity, or DODEA, schools.

The Interstate Compact addresses educational transition issues of military families such as eligibility, enrollment, placement and graduation, making it easier for military children to enroll in needed classes, play sports and graduate on time. Here are some of the ways states are helping you make a smooth move for your children.

IMMEDIATE ENROLLMENT

When leaving your school district, you can get unofficial records to carry to your new school. Your student will be able to enroll without delay, even before the official transcript arrives. If your child needs additional immunizations, you can enroll and take care of these requirements within 30 days.

PLACEMENT AND ATTENDANCE SUPPORT

Your children will be placed in appropriate required classes, advanced placement and special-needs programs while awaiting evaluation at their new school. That means your child won't be put in a "holding class" while your new school is taking the time to assess him or her. The Interstate Compact also enables a student to miss school for military-related reasons or to request excused absences before, during or after a deployment.

SPECIAL EDUCATION SERVICES

If your student is covered by the Individuals with Disabilities Education Act, federal law protects your child's right to receive the same services identified in his or her existing individual education program (www.militaryonesource.mil/family-relationships/special-needs/special-education-and-childcare/moving-with-an-individualized-education-program), or IEP. The receiving school may perform subsequent evaluations to ensure appropriate placement.

EXTRACURRICULAR PARTICIPATION

If your child is eligible, the new school will facilitate participation in extracurricular activities even if application deadlines or tryouts have passed.

GRADUATION

Rest assured that your high schooler's graduation will not be affected. Here are some examples of how the Interstate Compact assists with checking off graduation requirements:

- *Course waivers: If your child has already completed similar coursework, the new school shall waive courses required for graduation.*
- *Exit exams: The new school district shall accept your child's exit exams and achievement tests required to graduate from his or her previous school.*
- *Senior-year transfers: If your student changes school during his or her senior year, the two school districts will work together to get a diploma from the former school to ensure on-time graduation.*

SCHOOL LIAISONS

School liaisons are located at every installation and are especially helpful in dealing with your school transition issues. This local resource has well-established relationships with school

administrators, district officials and state departments of education and can help with your transition needs. School liaisons are available for all Department of Defense identification card holders, educators who service military students and community partners within the pre-K-12 education realm. School liaisons understand the military experience and are here to help with your child's move to a new school. Contact the school liaison at your current or acquiring installation (www.dodea.edu/Partnership/SchoolLiaisonOfficers.cfm) for help with:

- *Transition support, including school districts and boundaries*
- *Alternative school options and programs, including private, parochial, charter and home school*
- *School and community information nearby*
- *Special education*
- *Deployment support*
- *Compliance with the Interstate Compact*
- *Youth programs inside and outside of school*
- *Scholarship and grant resources*
- *College, career and military readiness*

You can also call Military OneSource to connect to an education consultant for help with everything from tutors to tuition. Don't wait until the move occurs. Call 800-342-9647 or set up a live chat today.

– Military OneSource

YOUR SCHOOL LIAISON CAN ASSIST WITH YOUR CHILD'S SCHOOL TRANSITION



School liaisons are your primary point of contact for all school-related matters, especially a school transition. The school liaison at your current installation can connect you to your new installation school liaison who will help smooth the transition to your child's new school. Let your school liaison help you and your family navigate school selection and youth sponsorship during this time of change. Find your school liaison at

www.dodea.edu/Partnership/schoolLiaisonOfficers.cfm



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Lessons from the Shore

I had experienced sheer moments of stress and panic, knowing Mark and I would not be there next to him to protect him – to pure euphoria as I watched our older son, Hayden, take control of the situation and coach his brother through the experience.

After looking at my

calendar, I'm still processing that it's the middle of July. Where did the time go? I'm afraid to blink because then it will be the middle of August and I'll be processing that my oldest son will officially be a senior in high school. I'm not ready. That seems to be my motto lately, "I'm not ready." I desperately seek moments where I feel calm and balance, but then I get slammed with a feeling of stress and panic. A great example was this morning. I got up at 5 a.m., determined to have a relaxing cup of coffee before the kids were up. I sat on the couch with my rescue dog, Jack, smiling as I felt the caffeine jump-start my body when, all of a sudden, Jack rolled on his back and kicked my full cup of coffee out my hand. I was drenched in hot coffee and ripped the couch cover off, hoping that coffee didn't soak my couch. This story seems to be the best analogy to describe the past few months that have been riddled with stress and anxiety to then be laced with euphoria and amazement.

Camp Cole is a new camp in the area that provides a place for children with all abilities to experience the outdoors. There are cabins giving them an opportunity to stay overnight, a beautiful lake to fish and kayak, as well as horse stables. To add to the overall experience, the camp also has a zero-entry pool. Broden's ABA clinic, the Unumb Center, hosted a day at the camp to give their clients an opportunity to experience what Camp Cole had to offer. Broden's older brother, Hayden, volunteered as a counselor earlier that month and wanted to show his brother

around the camp.

When we pulled the car up to the camp and walked into the building to sign up, the noise level was high and Broden started to plug his ears. He turned to me and said, "Ready to go home." I looked at Mark, "I don't know about this." After Mark gave me a "we packed everything, but the kitchen sink and I'm not getting back in our car to go home" look, I knew we needed to push through to see how far we could coax Broden through this camp. This was going to be painful and uncomfortable. Not just for Broden, but for me too.



SHORE THING: I have watched the video hundreds of times because it shows Broden's excitement and joy, but I also see Hayden's face of satisfaction and self-confidence after successfully teaching his brother something new.

Once we got outside to our assigned group, a team leader yelled, "Green Team, get ready to kayak and get your swimsuits on!" Of course, everyone had their swimsuits on under their clothes, except for us. Mark, Broden and I crammed into a family bathroom, threw our swimsuits on, and then ran down to the lake. I thought to myself, "Well, maybe we'll see if Broden will just sit in the kayak. That will be a win for us."

As usual, Hayden grabbed Broden and



said, "C'mon B. let's go." As always, Broden followed Hayden towards the lake while Mark and I looked on to allow Hayden to take over. Mark and I stood off to the side in awe as Hayden told Broden to pick up an oar and showed him how to paddle, "B, do what I do." As

Hayden would paddle to the left, Broden would paddle to the left. After a few minutes of instruction, Hayden went up to one of the camp counselors and said, "We're ready. Broden, get in the kayak. Sit in the front. I got the back."

As Broden walked to the kayak and continued to follow Hayden's instructions, Mark and I looked at each other and then started fumbling for our phones to document the moment. Just as I started to video, and Mark started clicking to take pictures, the camp counselor shoved them off into the lake. Then we heard, "Ok B, paddle like I showed you." Broden started to paddle and Hayden started to paddle with B in unison. They paddled all over the lake and were the

last kayak to come back to shore. I have watched the video hundreds of times because the video shows Broden's excitement and joy after trying something new, but I also see Hayden's face of satisfaction and self-confidence after successfully teaching his brother something new.

After watching Hayden with Broden on the lake, Mark and I said, "Hayden, you're in charge. We'll stand back and watch you work with Broden. We're here to help if you need us." Hayden nodded willing to take on the responsibility.

After changing out of our wet clothes, it was time for lunch. We walked into the cafeteria where all of the campers were getting their food, finding places to sit, and reminiscing about the morning activities. Conversations with laughter and clapping echoed through the cafeteria and Hayden noticed Broden getting very agitated, "Broden, do you want to leave and go to where it's quiet?" Broden answered, "Yea!" while plugging his ears and tensing up his body. Hayden motioned all of us to a picnic table outside under an overhang, "I think this will be better for you, B."

After eating, Hayden looked at the schedule to prepare Broden for the next activity. Mark and I could tell that Broden was starting to max out and was telling us he wanted to go home. Instead of taking charge of the situation, I looked at Hayden and asked, "What do you want to do?" Hayden looked at the schedule again and said, "Let me talk to one of the camp counselors. I don't think Broden is going to like the next activity because it's going to be too loud, so I'm going to see if we can slide in with another group and spend some time in the pool."

Minutes later, Hayden told us to get back into our swimsuits to join another group in the pool. Due to this decision, Hayden was able to extend our time at the camp and give Broden an opportunity to take part in an activity that he enjoyed. We were able to spend most of the early afternoon there that day at the camp, which was hours longer than we had originally expected. We left early, but for us, we called that day a win for our family.

That day at Camp Cole was like my morning coffee. I had experienced sheer moments of stress and panic as I watched Broden slide his life vest on by the lake, knowing Mark and I would not be there next to him to protect him – to pure euphoria as I watched our older son, Hayden, take control of the situation and coach his brother through the experience. As I would start to panic again with Broden getting upset at lunch, and wondering where could we go to calm him and encourage him to eat, Hayden was familiar with the camp and knew exactly where to go to set the conditions for Broden to keep going.

After looking through photos of that day and re-watching the videos of the two of them on the lake, I realized something. Intertwined in feeling uneasy and uncomfortable, I witnessed something that presented a sense of calmness. Mark and I had stepped back from Broden and we had the opportunity to see Hayden advocate for his brother. Hayden stepped up and took the initiative to alter Broden's environment to set him up for success, creating a priceless life lesson for Hayden, but also one for Mark and me as parents. They'll be just fine out there and it's ok to stay on the shore. •

PUZZLES & CAMO

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

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