Helen

The Journal of Human Exceptionality

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THE
Physician-Direct Support Professional
RELATIONSHIP

ARTIFICIAL INTELLIGENCE
Machine Learning
and
THE WHITE COATS

INCARCERATION
OF PEOPLE WITH
Disabilities

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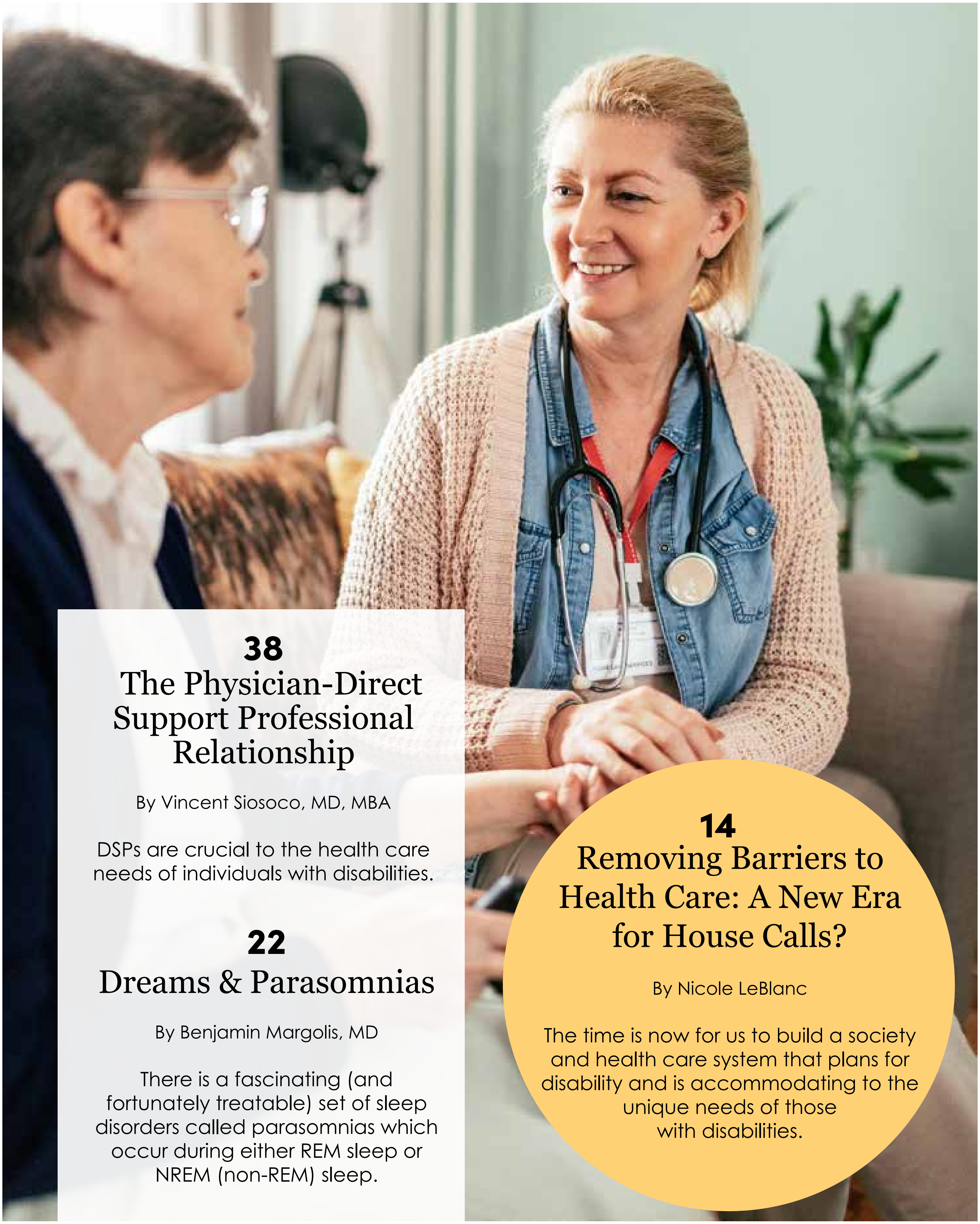

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The Journal of Human Exceptionality

HelenJournal.org

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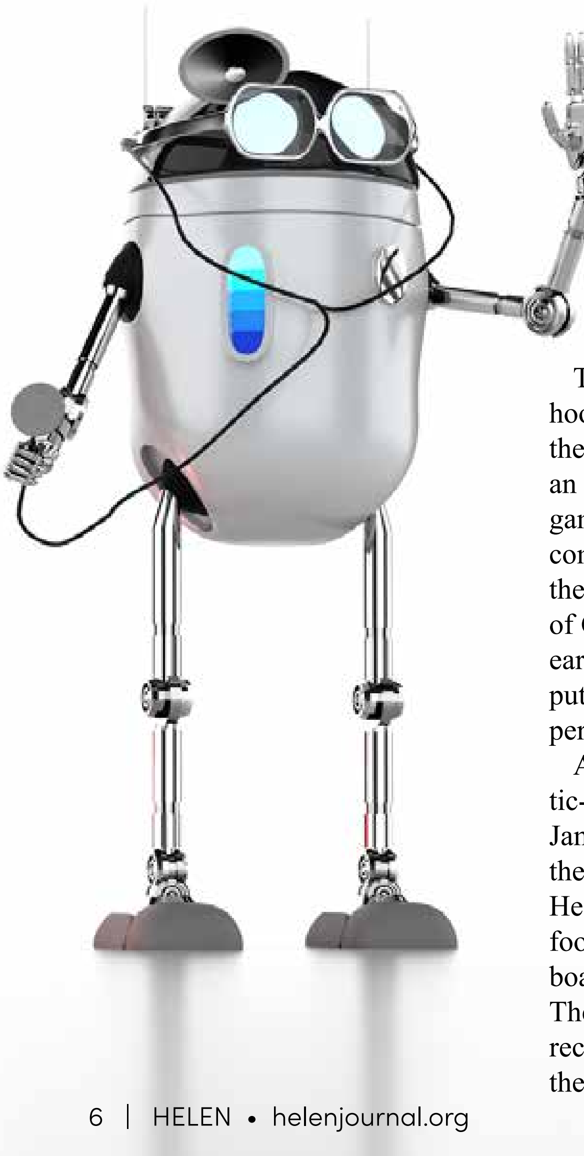
NOTHING IS WRITTEN - *EDITOR'S DESK*

Rick Rader, MD, FAAIDD, FAADM - Editor in Chief

Artificial Intelligence, **Machine Learning** and the White Coats



While on my recent flight flying home from San Francisco, I was seated next to a third grader who was getting his butt kicked by a computer-generated tic-tac-toe competition. During the four-hour flight I think the "human" was able to finish with a handful of ties.

Games like tic-tac-toe can be traced back to ancient Egypt on or around 1300 B.C. The British called the game "noughts and crosses." It has traditionally been one of the first games we learn to play as children. The difference between the paper and pencil version and the computer screen version is that the former required two to play. Not only did it require two players, but they were eyeball to eyeball of each other. Today's version doesn't require a breathing opponent but simply a video screen. To make matters worse, the odds of the human beating the screen becomes less and less as the data bank strategies become more evolved and proficient.

There did come a time in my childhood where we were introduced to the idea of playing the game against an invisible opponent. In 1952, the game OXO was developed by British computer scientist Sandy Douglas for the computer housed at the University of Cambridge. It stands as one of the earliest known video games. The computer player could consistently play perfect games.

An early version of the "electric tic-tac-toe" game was the creation of James Mason Prentice who founded the Electric Game Company in 1926. He invented both electric baseball and football games which were the first board games to use electric relays. The electric "tic-tac-toe" game was recently a finalist for induction into the National Toy Hall of Fame. It was nosed out by the Magic 8 Ball.

There was a major milestone in the "computer vs human" competition for bragging rights in intelligentsia.

Writing in The Atlantic, Marina Koren takes us back to that game-changing day. "There was a time, not long ago, when computers – mere assemblages of silicon and wire and plastic that can fly planes, drive cars, translate languages, and keep failing heart beating – could really, truly still surprise us. One such moment came on February 10, 1996, at a convention center in Philadelphia. Two chess players met for the first of six tournament matches. Garry Kasparov, the Soviet grandmaster, was the World Chess champion, famous for his aggressive and uncompromising style of play. Deep Blue was a 6 foot-5 inch, 2,800-pound supercomputer designed by a team of IBM scientists. Deep Blue won and the Genie was never able to be put back in the bottle.

Over the years, human intelligence was running neck and neck with motherboards and CPUs. With a sudden burst of speed, the human brain, our three-pound universe, was left in the dust. We (humans) used to be the unchallenged champion of creativity and intelligence. Artificial Intelligence (AI) has seemingly brought us to our knees in the realm of boasting "smarty pants."

Beyond games, we can see the impact when machine learning dons the white coats. Reports from the Vodafone Institute for Society and Communications share that "Researchers at an Oxford Hospital have developed an AI that can use heart and lung scans to diagnose deadly diseases. While this has also been routinely done by human doctors, computer programs promise to yield clearly better results than even the best medical professionals, as it is estimated that at least one in five patients are misdiagnosed. Earlier, more accurate prevention and fewer unnecessary operations could lead to enormous cost reductions."

Further evidence that AI can outperform MD comes from AI engineer George Zarkadakis. For human physicians, the challenge of making correct diagnosis is huge. It is estimated that in order to be at top of medical knowledge human doctors must spend 160 hours per week reading new research papers. IBM Watson's AI does that at a fraction of the time. On top of this it has the ability to search through millions of patient records, learn from previous diagnoses, and improve the reasoning links between symptoms and diagnosis. The result? IBM Watson's accuracy rate for lung cancer is 90%, compared to a mere 50% of human physicians."

rly version of The Electric Game Co.'s Tic Tac Toe game

One of the reasons that AI may have the upper hand at making an accurate diagnosis is due to the fact that machines are not anchored to following conventional and predictable patterns associated with human physicians. Humans are hardwired to follow the facts. Machines can use what is known as "counterfactual methodology." This pattern of thinking was first formulated by, of all things, a human physician. Sir Arthur Conan Doyle, both a physician and author of the Sherlock Holmes mystery novels, promoted this line of thinking. Holmes constantly adhered to his creative dictate, "When you eliminate the impossible, whatever remains, no matter how improbable, must be the truth."

One of the drawbacks of Artificial Intelligence is its inability to draw on general reasoning. This is still currently the domain of us mortals. General reasoning has perhaps been the single most important instrument in conjuring up strategies to assist people with disabilities in doing what appeals to them. We have not yet been able to convince, influence or program machine-learning complexes to appreciate, imagine or conjure up the potential, capacity, motivation, and determination of people with different abilities.

Decades ago, I set out to provide a simulation experience to my medical students and residents, to give them a taste of disabilities. Of course, the obvious ones were easy to replicate — earplugs for hearing impairments, blindfolds for vision impairments, gloves for haptic impairment, wheelchairs for mobility impairments, and rice in the shoes for neuropathic conditions. But I was unable to figure out a way to replicate intellectual disabilities.

I consulted with IBM software engineers. While they were able to send humans to the moon, they were confused as to how to program a computer to think in ways in which people with limited cognitive reserves responded to everyday trials and tribulations. They were unable to figure out how to program computers to think with only a fraction of their accumulated knowledge. It was the nature of the computers to reach into their vast reserves of collective wisdom from every discipline and use them to emerge as winners. The engineers could not program the computers to discard available information; they could not compel the computers to think with one arm tied behind their back. They finally put up the white flag and admitted that in their pursuit of perfection, there was no allowance for suboptimal thinking.

I think the human brain still remains the winner in the clash with the machine titans. For one thing, we have to give the brain credit for accepting, acknowledging and recognizing the inherent shortfalls of the human condition. I hope that until the day when AI and machine learning can incorporate that into their programs, that humans remain in charge and continue to exercise and pursue that most human of human qualities — acceptance and inclusion.

Why Helen

Alone we can do so little;
together we can do so much.
- Helen Keller

HELEN: The Journal of Human Exceptionality pays tribute to Helen Keller. Ms. Keller is perhaps the most iconic disability rights advocate and an example of how an individual with complex disabilities found and used her stamina, perseverance, resilience and determination to accomplish great things.

Helen personifies the spirit, mission and vision of The Journal of Human Exceptionality. Her remarkable life is a reflection of her determination; she inspired us with her words, "What I'm looking for is not out there, it is in me."

"Nothing is written."

This quote from T.E. Lawrence implies that nothing is inevitable, life consists of choices, and how the individual can make an impact on his/her destiny. The disability community continues to reinforce and remind me of this; hence the name for my monthly musings.

- Dr. Rick Rader

Collaborative Organization Mission Statements

Helen: The Journal of Exceptionality is proud to be endorsed by the nation's leading organizations that advocate for people with Intellectual and Developmental Disabilities (IDD).

The AADMD is resolved:

To assist in reforming the current system of healthcare so that no person with IDD is left without access to quality health services.

To prepare clinicians to face the unique challenges in caring for people with IDD.

To provide curriculum to newly established IDD training programs in professional schools across the nation.

To increase the body and quality of patient-centered research regarding those with IDD and to involve parents and caregivers in this process.

To create a forum in which healthcare professionals, families and caregivers may exchange experiences and ideas with regard to caring for patients with IDD.

To disseminate specialized information to families in language that is easy to understand.

To establish alliances between visionary advocacy and healthcare organizations for the primary purpose of achieving better healthcare.

It is the purpose of the American Academy of Developmental Dentistry (AADD) to establish postdoctoral curriculum standards for training dental clinicians in the care of patients with IDD, to establish clinical and didactic training materials and programs to promulgate these standards, and through its certifying entity – the American Board of Developmental Dentistry – to grant board-certification to those dentists who have successfully completed these training programs.

The American Academy of Developmental Medicine (AADM) is a medical society dedicated to addressing the complex medical needs of individuals with intellectual and developmental disabilities across the lifespan. It incorporates clinician training and awareness, teaching, advocacy, research, board certification, health equity, interdisciplinary collaboration, inclusive care delivery models and shared decision making.

AAHD is dedicated to ensuring health equity for children and adults with disabilities through policy, research, education and dissemination at the federal, state and community level. AAHD strives to advance health promotion and wellness initiatives for people with disabilities. AAHD's goal are to reduce health disparities between people with disabilities and the general population, and to support full community inclusion and accessibility.

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www.medicaiddental.org

James T. Brett
Named Chairman of the **President's Committee for People with Intellectual Disabilities**

According to the New England Council's website (NewEnglandCouncil.com), the organization's President & CEO, Jim Brett, earlier in the year, was designated by President Joe Biden as Chairman of the President's Committee for People with Disabilities (PCIPD). Earlier last spring, President Biden appointed Jim to serve on the Committee. Jim previously served as a Committee member under Presidents George W. Bush and Barack Obama, including a term as Chair from 2011 to 2013.

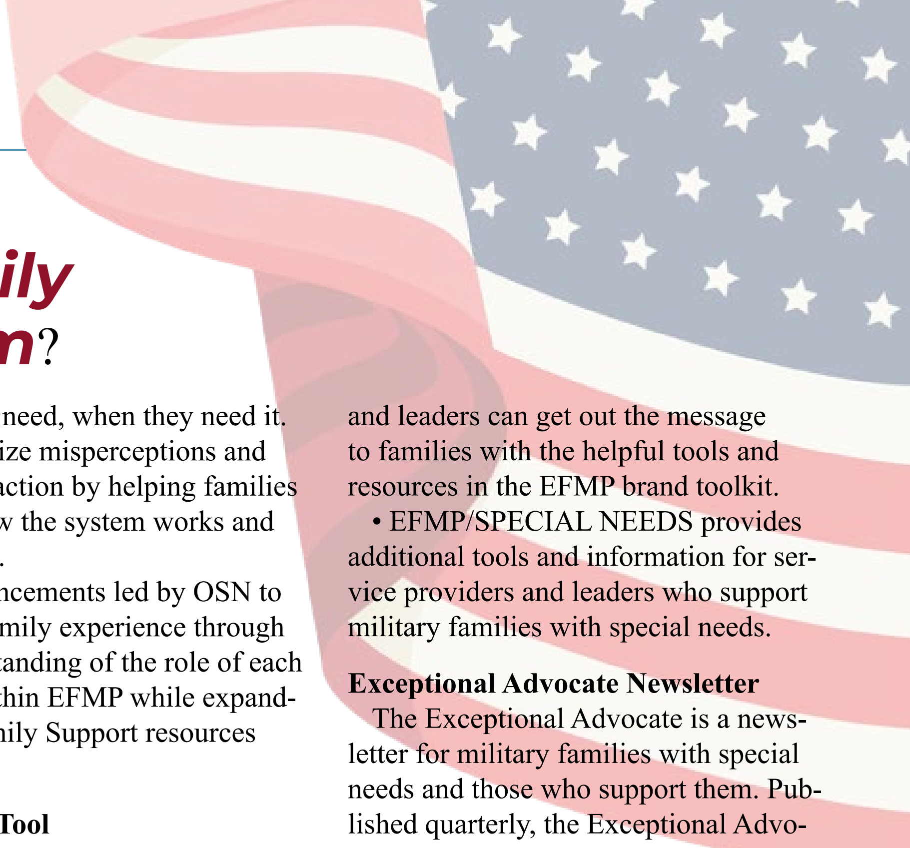
In recent months, Jim has also been recognized by several educational institutions for his advocacy in support of people with disabilities. During commencement exercises on May 14, 2022, Franklin Pierce University honored Jim with its Honorable Walter R. Peterson Citizen Leader Award. The award is named for New Hampshire's distinguished 72nd governor and the second president of Franklin Pierce University, a longtime New England Council member.

On May 15, 2022, Jim was honored to deliver the commencement address to the class of 2022 at the Berkshire Hill Music Academy (BHMA) in South Hadley, MA. BHMA is a unique college-like program for young adults with intellectual and developmental disabilities. And finally, on May 20, 2022, Jim received an Honorary Doctor of Business and Commerce degree from NEC member Merrimack College.

Jim Brett is the President and Chief Executive Officer of The New England Council, the nation's oldest regional business association. He was appointed to this position by the Council's Board of Directors in October 1996.

Under his leadership, The New England Council has become the region's premier business advocacy and networking association. During his tenure, revenues have grown significantly, membership has increased tenfold, and the organization has expanded its programming to offer upwards of 60 events annually throughout the six New England states and in Washington, DC. The Council is widely respected by business leaders and policymakers alike for its non-partisan, consensus-based approach to policy advocacy. As a result, in recent years, Jim Brett has led the Council's successful and impactful federal advocacy on a wide range of critical economic issues, including energy, financial services, health care, education and workforce development, technology, transportation, trade, and more.

Prior to joining the Council, he served for 15 years as a member of the Massachusetts House of Representatives. During that time, he served as a Chairman of several of the most influential committees in the Massachusetts legislature, including the Committee on Banking, the Committee on Taxation, and the Joint Committee on Congressional Redistricting. As a State Representative, his legislative priorities included providing tax relief for key Massachusetts industries, creating high-wage jobs, developing and retaining a skilled workforce, and fostering an overall business climate that supports economic growth and prosperity for all residents.



What's New With the *Exceptional Family Member Program*?

The Department of Defense Office of Special Needs is committed to helping families with special needs thrive in military life. The Exceptional Family Member Program does this through identification and enrollment (Medical), assignment coordination (Medical and Military Personnel) and family support. The more families understand how EFMP works across these three parts, the better their experience can be.

Each branch of service has its own mission and history with EFMP. However, there has been a continual focus on enhancing EFMP to establish more standard procedures across the services to make it easier for families to find what they need, when they need it. We can minimize misperceptions and increase satisfaction by helping families understand how the system works and what to expect.


NAL FAMILY SUPPORT
FOR YOUR MILLIFE

EFMP Exceptional Family Member Program

ther, so our assistance is custom-tailored as well. The EFMP Family
llation can connect you to the right resources, wherever you go – so
s needs. Call on our support.

ng specialty consultations, planning tools, non-medical counseling
all or visit https://www.militaryonesource.mil/ | 800-342-9647

SUPPORTED BY MILITARY ONE SOURCE

Recent enhancements led by OSN to improve the family experience through greater understanding of the role of each component within EFMP while expanding EFMP Family Support resources include:

EFMP & Me Tool

EFMP & Me is a new online tool to provide families direct access to information and resources in each of the three components.

- Offers 24/7 access, at home or on the go, through a digital application.
- Provides family members with a tailored, streamlined and supportive digital experience to locate guidance and information when and where needed.
- Gives service providers and military leaders an additional information source to use and to recommend to families.

Improved Communication With Families

EFMP Family Support focuses on sharing information with families to better support them and help them improve their self-advocacy skills.

- EFMP Family Support Feedback Tool— Provides a mechanism for families to give feedback about their recent experience with installation EFMP Family Support. This feedback will help OSN and the military services with program improvement and policy development.
- New brand and improved messaging — Communicates clearly and effectively that EFMP is evolving to better meet the needs of service providers and families. Service providers and leaders can get out the message to families with the helpful tools and resources in the EFMP brand toolkit.
- EFMP/SPECIAL NEEDS provides additional tools and information for service providers and leaders who support military families with special needs.

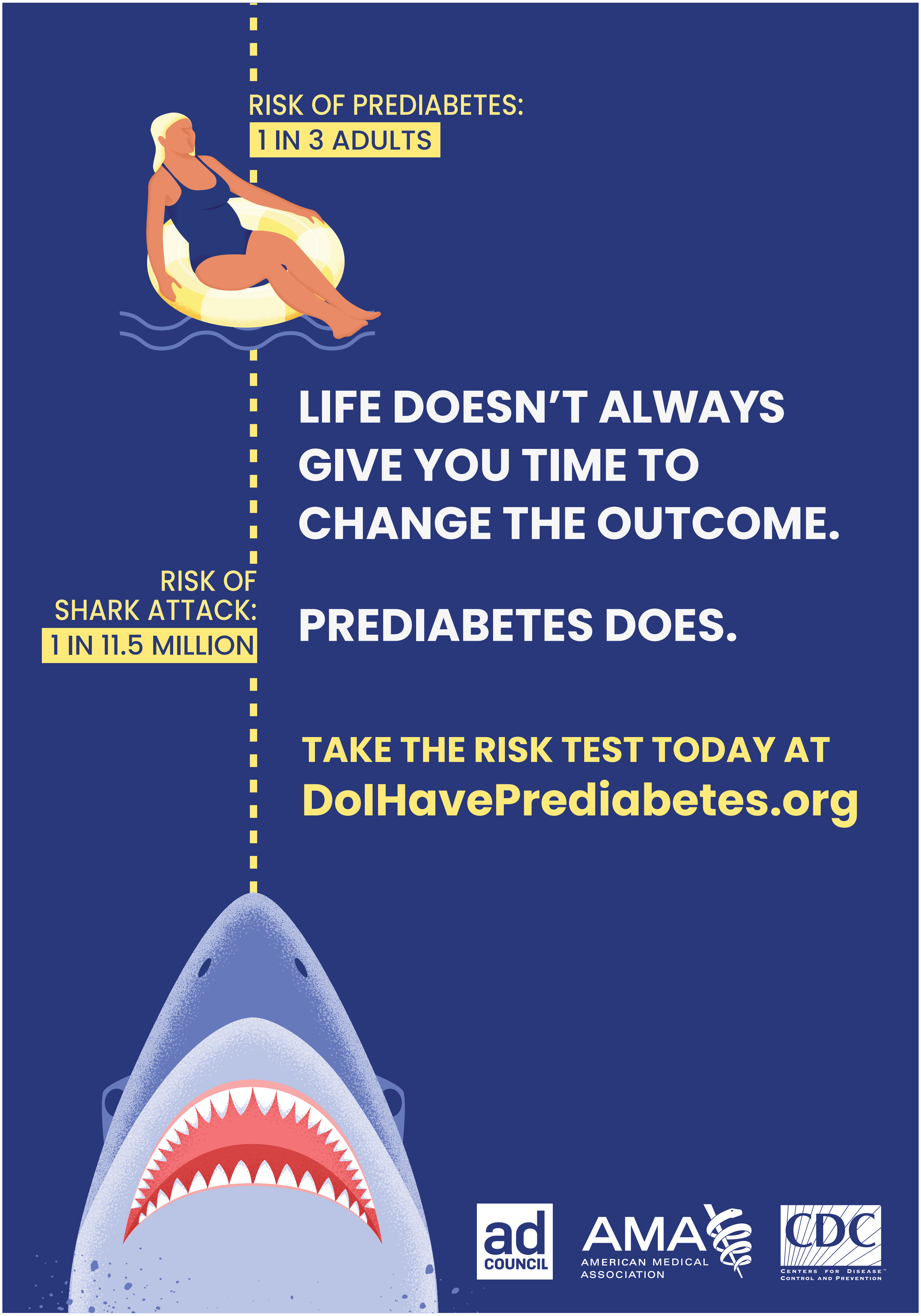
Exceptional Advocate Newsletter

The Exceptional Advocate is a newsletter for military families with special needs and those who support them. Published quarterly, the Exceptional Advocate focuses on updates and information from EFMP.

Office of Special Needs EFMP Podcast Series

Tune in to this podcast series from the Office of Special Needs, where subject matter experts share information and resources of interest to military families with special needs members. Listen at your convenience to a range of topics including education, PCS moves, long-term and financial planning, deployment and much more. Get to know EFMP & Me and how it can help you and your family member with special needs overcome challenges and thrive in military life.

Learn more about the EFMP & Me tool and other program highlights to help your family or to share with other families with special needs. Contact your nearest installation EFMP Family Support provider or contact Military OneSource special needs consultants for free and confidential special needs consultations to help you navigate services for your family. You can schedule appointments 24/7 by live chat or calling 800-342-9647, or check out OCONUS calling options. (From Military-OneSource)



A Clinical Pearl

By Rick Rader, MD, FAAIDD, FAADM

For clinicians in the field of developmental disabilities finding novel, innovative and unorthodox approaches to successfully performing medical examinations offers both rewards and challenges. The use of menstrual blood as a blood sample may check off all the boxes in the ID/DD clinician's toolbox.

Virtually every clinician involved in treating patients with intellectual and developmental disabilities has had a multiple of new patients appear without the results of a recent blood test. We are used to seeing notes in the health records that report, “Blood test deferred at this time,” or “unable to draw blood from this patient.”

There are several reasons for a medical assistant, nurse or physician to be unsuccessful with obtaining blood samples. The patient could be uncooperative due to sensory, negative past experiences, inability to understand both the need and procedure for drawing blood, anxiety, anticipatory pain or dehydration. There is a class of patients, regardless of their cognition that are simply “hard sticks.” Most clinicians adhere to the “two and out policy.” If you can't get blood after two (sticks) attempts, give up, or call in the one person in the office who could do it blindfolded (and maybe they should be designated to be the first in line with those more challenging patients).

Stephanie Demarco, PhD, writing in the newsletter DDN (Exploring Drug Discovery and Development) introduces us to a novel solution to this ongoing problem: “Whether from a finger prick or drawn from the arm, blood is our window into health. A few drops of it can reveal if someone is at risk for developing diabetes, pregnant, or has early signs of cancer. Until recently, clinicians and researchers have ignored a blood sample that doesn't require a need or a doctor's visit to obtain. In fact, much of the population has been throwing it away every month for millennia.”

> “Stop mansplaining menstruation, we've got this.”
>
> - Silvia Young,
> “My FemTruth:
> Scandalous Survival Stories”

The novel solution is “menstrual blood,” The clinical reality is that “blood is blood.” Historically, clinicians never acknowledged the diagnostic potential of this monthly blood sample. In fact, menstrual blood might be thought of as “blood plus.” In addition to the blood, the body sheds what we call “menstrual effluent,” a fluid that contains endometrial tissue with viable cells, immune cells, nucleic acids, proteins, and even microorganisms from the vaginal microbiome. Indeed, menstrual blood contains more than 300 unique proteins that are not found in peripheral blood, along with a specific composition of immune cells.

Demarco provides, “Unlike a typical needle draw, collecting menstrual blood is a non-invasive process. The menstruating public uses at least one of the many menstrual products available such as menstrual cups. Period underwear, tampons, and pads. Because people can collect menstrual blood using these passive methods, it is a blood sample that can be collected and analyzed from the same person at multiple time points during one menstrual cycle and regularly every month, giving clinicians more precise insight into a patient's health.”

There are ongoing programs demonstrating that clinicians can use menstrual blood to monitor health conditions like diabetes and thyroid disease, as well as endometriosis and cancer. This non-invasive and easy-to-use collection methods suggests that monitoring menstrual blood will increase access to preventative and reproductive healthcare and allow for the earlier diagnosis and treatment of often difficult-to-diagnose health conditions.

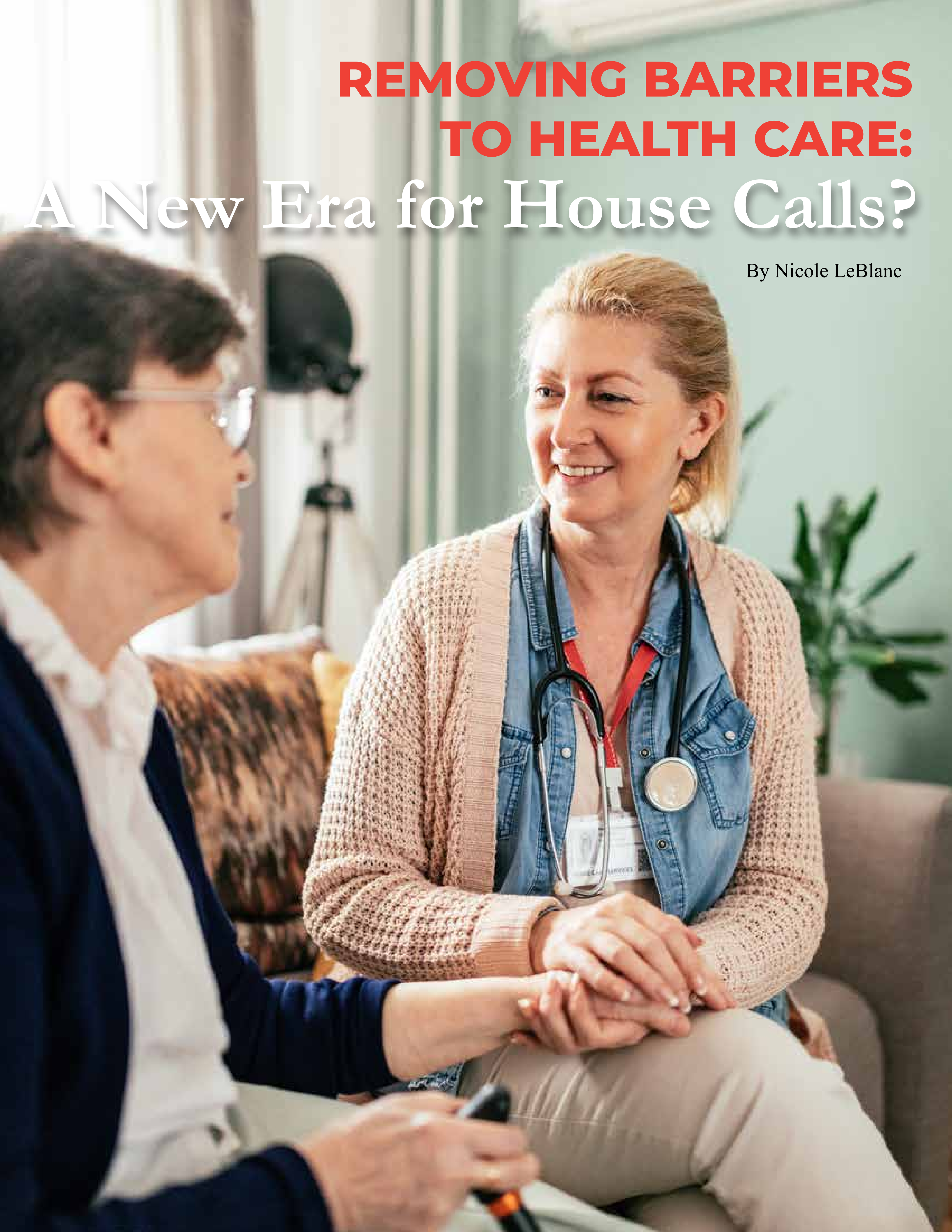
And while menstrual blood limits its use to age-specific females, it presents a great opportunity to clinicians to review and follow abnormalities in blood samples that for many women with disabilities have long been “deferred.”

For more information: www.drugdiscoverynews.com July, 2022 Stephanie Demarco, PhD, “Menstrual blood holds the key to better diagnostics.”

REMOVING BARRIERS TO HEALTH CARE:

A New Era for House Calls?

By Nicole LeBlanc



The COVID-19 pandemic has led to big innovations in health care, and telehealth has been especially beneficial during this time. Telehealth provides remote medical care over the internet. It is a great way to maintain access to preventive and urgent care while limiting the spread of COVID-19 that comes with traveling to doctors' offices. The convenience of not having to travel to doctors' offices is especially important to people with disabilities, given that many of us don't drive and have transit barriers. And while telehealth is great for things like going over blood test results, in-home medical care is another great way to provide healthcare.

House call visits for people with intellectual and developmental disabilities could help meet our unique needs and provide the care that we need. In the medical field, a house call is when a doctor or other medical provider visits a patient in his or her own home to give care. Doctor house calls have been around since the 1930s, during the Depression era. In fact, house calls made up 40% of doctor-to-patient interactions at that time.[1] To talk about house call visits as a way of providing more inclusive healthcare, I interviewed:

- Dr. Robert Baldor from UMass Medical School
- Dr. Gia Richmond, Director of Inclusive Living Services at the Arc of Montgomery County Maryland
- Dr. Vincent Siasoco of New York City who also serves as the Clinical Director for Special Olympics

Access and Attitudes

Public health promotion programs have not adequately addressed the unique accessibility barriers the developmental disability community faces. Studies show that people with developmental disabilities have higher rates of emergency room use, longer stays in hospitals, and are less likely to receive preventive-care screenings and checkups.[2] In part because of this lack of care, we also have higher rates of chronic diseases compared to the general population – for example, obesity, diabetes, heart disease, and high blood pressure.

The COVID-19 pandemic has created greater public awareness on health disparities and attitudinal barriers that people with disabilities deal with on a day-to-day basis. COVID-19 has allowed the media and advocates alike to shine a spotlight on the negative impact of ableism and racism in our health care system. As someone who has experienced how poorly our health care system does in meeting the needs of people with developmental disabilities, I see the COVID-19 pandemic as an opportunity for further advocacy, education and awareness.

> “The time is now for us to build a society and healthcare system that plans for disability and is accommodating to our unique needs.

The health care challenges people with developmental disabilities and their families face on a regular basis are enormous and need to be highlighted. The time is now for us to build a society and health care system that plans for disability and is accommodating to our unique needs. If we all live long enough, we will all join the disability club. So, the time is now for us to build a society and health care system that plans to live with disabilities in the 21st century.

What Are the Benefits of Doctor House Calls?

Doctor house call visits have many benefits for vulnerable populations. They allow the doctor to get to know patients better by observing them in their own environment. It gives doctors a better idea of treatment procedures that may or may not work. It allows for a better bedside manner because the doctor is focused on one person only rather than a waiting room full of people. By doing this we can provide more individualized or person-centered care.

One thing I must stress is that telehealth also has its limitations in meeting our unique needs. Many basic things like exams that require 'hands-on' touch need to be done in person by doctors. Telehealth is good for finding out blood test results or general health screening over a phone or computer. However, many of us have greater needs that require face-to-face visits. Thus, in the developmental disability world the benefits of house call visits often outweigh telehealth when compared to the non-disabled population. Given that we are often high users of medical care due to our chronic lifelong conditions. Lastly, telehealth requires high-speed reliable internet, something that is hard to come by in many rural areas in our country.

The Benefits According to the Doctors

Dr. Baldor talked about how it's like night and day. Receiving care in one's home is patient-centered, and it's a great way to remove the difficulties of getting into the office: "The office environment is anxiety provoking; you can't be yourself, whether that's related to interacting with unfamiliar individuals, communicating awkward medical problems or dealing with mobility barriers." On the other hand, seeing someone at home is like night and day, you actually get to see the person in their real environment. "They are just more relaxed with the presentation, and it just makes the whole visit go easier." He also said that it takes away a little bit of the power dynamic that's there, "because you are working on their turf not yours."

Dr. Siasoco shared how house call visits offer "comfort and ease for patients and their families when they see a doctor that they are familiar with coming to their home setting." The great thing about this, he says, is that there are no issues with transportation or lengthy wait times in a waiting room that's bustling, noisy, and distracting. There is also no worrying about equipment or supplies. "In general, the beauty of house calls is just that comfort level – and that comfort level, and that familiarity with your own personal doctor coming to visit the individual where they live, really contributes to a better relationship, and better communication." This is important. Offices like the ones at many health centers have white walls and can be scary for some people, he says. In situations where a patient is already nervous or not really comfortable around physicians, it can be a big challenge, but if you see them in their home, it can really contribute to improving the relationship and the doctor's ability to perform the physical exam, especially if they live with family or extended family that can offer support.

Dr. Richmond, of the Arc of Montgomery County, Maryland, says based on her observations house calls are a personalized service that allows a doctor to come to the patient's environment where they know you, where you live, and what your exact needs you may have – and it's easier to make recommendations on adaptive equipment that actually works. As a doctor, Dr. Richmond says, it helps you avoid situations where people get prescribed adaptive equipment that may not work or fit a person's needs, such as equipment being too big or small. In Dr. Richmond's opinion, the best thing about this model of care is that it leads to a better bedside manner because the doctor's attention is solely focused on the individual in that home and seeing them for longer appointment times. This allows doctors to be more attentive to the needs of individuals, especially as health declines and changes over time.

Will the Pandemic Lead to a Return of House Call Doctor Appointments for Patients With Complex Needs?

When I asked this question, the reaction from the doctors I interviewed was mixed. Dr. Richmond said in the short run we may see more house call visits but not long term. Given that

the field of medicine is not one-size-fits-all. House call visits may work for some but not for others, but Dr. Richmond says that telehealth is definitely the wave of the future, as we have seen during this pandemic.

Dr. Baldor says he does not see us returning to a 1930s version of house calls, but we are seeing some parts of the medical office go out to homes via a van. An example of this is an Advanced Practice Clinician (APC) who goes to a client's home to get a urine sample to bring to the van to check for a UTI. So, if it looks like a UTI, often they will have medicine they can give right away. During this process, the APC is communicating by phone with the doctor.

Dr. Siasoco shared that the pandemic may lead to a return in some settings – given that when doctors think of people with IDD they always try to think of where they live and their environment; often it is a congregate or group setting. Many such settings have rules on who can come in and out where Dr. Siasoco works in New York City. He sees somewhat of a return to the practice of house calls but he's not sure how much. Right now, one cool thing they are doing in New York City is having a phlebotomist go into group homes and draw blood there. In today's world, this model of care is a great thing but the concern is obviously being able to do it in a safe manner that ensures everyone has access to PPE. From the rural-America perspective, he says doctor house calls would be a great thing to do given that rural areas are not that dense.

> “
> Receiving care in one's home is patient-centered, and it's a great way to remove the difficulties of getting into the office

What Are the Challenges for Doctors in Making House Calls?

According to Dr. Richmond, there is not enough of a pool of doctors available to make house call visits. As it stands currently, a single doctor in her area would need to make up to 200 house calls which is not very sustainable. Plenty of the doctors are skeptical of adopting this method of patient care especially during the COVID-19 pandemic. They view it as a health hazard to have to come in contact with numerous people while making house calls in unregulated areas. Therefore, it will also take a lot of time and resources to train doctors on the mechanisms of making house calls and how to effectively deal with patients in an environment that's not a hospital or a doctor's office. Dr. Siasoco suggests that such doctors need to be equipped with proper PPE if they are to make house call visits and the patient's environment would have to be appropriately sterilized before such visits.

What Infrastructure Is Needed to Make House Call Doctor Visits Successful?

The first requirement to support this model of care is an increase in the number of doctors looking to do this type of work. As it currently stands, most doctors are skeptical of the measures that are in place to ensure their safety, especially against COVID-19.[3] The second is effective training that will equip doctors with the knowledge on this model of care.

Offering a higher payment for this type of care is definitely needed. This is where payment reform comes into play. Payment reforms are necessary because the doctors performing house call visits end up using more of their own resources – like gas and carrying around a lot of medical equipment that would have otherwise been avoided were the patients visiting hospitals, doctor's offices, or clinics. One challenge with this is that doctors may see fewer patients in order to make this model work, therefore they should be paid more. By paying a higher rate for house call visits, it would help to make up for the fact that they would be seeing fewer patients. Patients benefit greatly from this model because the doctor is 100% focused on them. Rather than wasting time worrying how to keep the clinic financially sound. The third thing is funding to pay for the infrastructure needed to expand these options, especially in rural areas. Infrastructure such as internet that is necessary for the effectiveness of telehealth is lacking in most rural parts which need the house call visits most.

Nicole LeBlanc is Advisory Group Coordinator of the National Center on Advancing Person-Centered Practices and Systems (NCAPPS).

NCAPPS is an initiative from the Administration for Community Living and the Centers for Medicare & Medicaid Services that helps states, tribes, and territories implement person-centered thinking, planning, and practice in line with U.S. Department of Health and Human Services policy.

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A **Behavior Analyst** With a Mold Allergy

By Ley Linder, MA, M.Ed, BCBA

"You can't do that! People with dementia can't learn!" he said with an arrogant assertion and a tinge of ridicule. I nodded back to my graduate academic advisor, while my inner monologue feverishly quipped back, "Well, buckle up! We are in for quite the ride, given I just moved into a moldy motel room (true story!), with everything I own packed into an aging Mazda, and recently signed for $15K in student loans that I need to last me 12 months!" This was the first time I ever mentioned to anyone, beyond family, my desire to find the intersection of behavior analysis, intellectual disabilities, and dementia - and make it my home.

Formally, I have a Master of Arts in Gerontology from Appalachian State University, as well as a Master of Education, with an emphasis in Applied Behavior Analysis, from Arizona State University. However, in hindsight, my education began in the 1970s, a decade before my birth, when my dad was a Direct Support Professional (DSP) working with adults with ID/RD.

INTRODUCING!

BEHAVIOR: Gateway to Inclusion

Emily Dickinson, long regarded as one of the most important figures in American poetry, cuts to the chase when she reminds us that "Behavior is what a man does, not what he thinks, feels, or believes."

That quote is probably what the average person understands when they witness aberrant, atypical or disruptive behavior on behalf of an individual with an intellectual and developmental disabilities.

Behavioral therapists see behind that marquee quote. They understand that thinking, feeling and believing is the basis for all behavior. Since behavior is communicating, we don't always have a translator to clue us in to "what exactly are they trying to communicate?"

In terms of inclusion, community participation and acceptance, "behavior" represents the keys to the kingdom. An individual's behavior announces what we can expect from an interaction. In reality, it serves as the "calling card," an "invitation," and also "coming attractions."

Acceptable standards of behavior (based on community and social standards) becomes the ticket to work, to form relationships, partnerships and companions. Behavior lies in the intersection between health, self determination and an array of choices and options. We now appreciate the connection between behavior, positivity, disability and longevity

HELEN is pleased to present a series devoted to "behavior." Leading the way is Series Editor Ley Linder, a respected and accomplished board-certified behavior analyst. We are delighted to have Ley introduce us to a better understanding of behavior and the often-misunderstood field and science of behavioral analysis, behavior modification, behavioral support and behavioral intervention.

- Rick Rader, MD
Editor-in-chief

By the time I was a young child, my father had taken his skills, climbed to the top, and became the Executive Director of a large residential provider serving individuals with ID/RD. After a day of watching “Reading Rainbow” or “Sesame Street” in elementary school, I would return home to hear about the efficacy of interventions for a man who would “eat frozen pizzas right out of the freezer in the grocery store.” Not only was this shocking to hear as a six-year-old, but it was also shocking as an adolescent to realize Prader-Willi was this man’s diagnosis, not his name.

My mom’s impact on my education is similar, as she too worked with people with ID/RD in the 1970s. In fact, my parents met while working on the same “units,” where my mom was a staff nurse and my dad worked as a DSP. Mom ascended too, despite her “Nurse Ratched” moniker flirtatiously given to her by my dad on the weekend shifts they shared. She is an Adult Nurse Practitioner who specializes in psychiatry and works exclusively with adults with a dual diagnosis of ID/RD and mental illness. My high school transcript would indicate that my skill sets were somewhere on the continuum of early dismissal, stained glass class, and detention. Ironically, and at the same time, educators in Columbia, South Carolina, generously donated my parents a high school diploma with my name on it, I could diagram the psychobehavioral components of feces smearing behaviors in a profoundly intellectually disabled, non-verbal adult, complete with a plan of care that did *not* involve anti-psychotics. Thanks, mom, what a tremendously helpful skill in college bars!

Academia put a few letters behind my name, but my education regarding people with ID/RD started long before I worried about poor Prader or developed “kennel cough” from that moldy motel room. My story is a generational one and here I am today, a Board-Certified Behavior Analyst (BCBA), specializing in behavioral gerontology and the behavioral presentations of neurocognitive disorders, as well as a business owner and, now, HELEN Journal contributor. With introductions now complete, let’s get to why Dr. Rick Rader humbled me with an invitation to write periodically for HELEN – to start some “good trouble.” Let’s get to it, shall we?

For Behavior Analysts (BAs), the question of “where do you work?” has the potential to be a pedestrian one, as many work in schools, ABA clinics, and universities. BAs can also work in homes below the poverty level or mansions with security guards at the entrance, have roles assisting with end-of-life support, provide informal grief counseling, assess prison inmates, advise hospitals, work with physicians, and sit on national boards. Or, so I’ve been told. Every setting is unique, just like the individuals we serve, yet everything is always familiar. People with intellectual disabilities need more advocates, caregivers need more emotional support, doctors need more education, and everyone needs more funding. Given all the needs, there is only one acceptable answer to the question when asked, “Where do BAs work?” We. Work. *Everywhere*.

> “
> Behavior Analysts must adapt our skills beyond the linear, formulaic approach that turns people into data.

As a general rule, the populations served by BAs are not as diverse as in the aforementioned settings. Depending on your reference source, approximately 75% of BCBAs work with people with an autism spectrum disorder. My current practice primarily serves adults with a dual diagnosis of ID/RD and mental illness who live in residential group homes. With the aid of mischievous wording from a mentor, I have also developed a sub-specialty working with criminal offenders with intellectual disabilities. Then there is the mold-breaking holy grail – aging, intellectual disabilities, and behavior analysis.

In the future, Behavior Analysts must adapt our skills beyond the linear, formulaic approach that turns people into data. BAs must be more inclusive in the populations served and settings worked, which should be guided by the ability to improve people’s lives, without regard for diagnosis, age, or setting. The roles BAs serve go far beyond specific expertise in evidenced-based practices and necessitate being advocates to combat diagnostic overshadowing, training caregivers, and serving as leaders of interdisciplinary teams – to name a few. The vast potential of BAs to serve a broad continuum of needs for people posits us as leaders in day-to-day care, but also the global support of all people impacted by and serving individuals with ID/RD.

For behavior analysis, as a field, to survive, let alone thrive, we must shatter the molds and torch the ivory towers to be inclusionary of *all people. Everywhere.*

Ley Linder, MA, M.Ed, BCBA is a Board-Certified Behavior Analyst with an academic and professional background in gerontology and applied behavior analysis. Ley’s specialties include behavioral gerontology and the behavioral presentations of neurocognitive disorders, in addition to working with high-management behavioral needs for dually diagnosed persons with intellectual disabilities and mental illness. He is an officer on the Board of Directors for the National Task Group on Intellectual Disabilities and Dementia Practices, works closely with national organizations such as the National Down Syndrome Society, and is the owner/operator of Crescent Behavioral Health Services based in Columbia, SC.

Dreams & Paraso

A dream is among the most mysterious realms of human experience: we are conscious but not conscious. We can control our journeys through them, but perhaps not completely. We can remember them, but often in fragments and whispers of memory. The rules of linear time may not apply and recall may not be perfect. Ask yourself – what did you dream last night? How long did you spend dreaming? Do you remember them all? What senses do you remember being engaged? Did you dream in color or black-and-white? Were you able to smell, or to taste in your dreams? Did you have one dream or more than one? Did you have a nightmare? What made it a nightmare? Most difficult of all, what did your dreams mean? Is there a way to find out?

Experimental scientists can now create tools with a scale larger than the earth itself, when in the LIGO (Laser Interferometer Gravitational-wave Observatory) experiment, the brightest minds in physics detected and translated the faintest traces of the Big Bang into a sound we can hear with our ears.[1] Things seemingly

mnias

By Benjamin Margolis, MD

impossible to detect are now within our reach – but the journey within, into dreams and their meaning, remain largely hidden.

Clinical neuroscientists and researchers can study the workings of the living brain in great detail and resolution. We can determine brain structure with CT (Computer Assisted Tomography) and MRI (Magnetic Resonance) imaging. Using an MRI technique called fMRI, we can observe networks within the brain functioning in real time. We can observe the electrical discharges of neurons with a routine EEG (electroencephalography) by placing electrodes on the skin. We can observe the magnetic fields generated by groups of neurons communicating with each other (MEG, or magnetoencephalography). We can even see the uptake of glucose or individual neurotransmitters such as dopamine in specific regions of the brain to help us diagnose conditions such as Parkinson's disease.

In sleep, we have polysomnography (PSG), which includes EEG and captures sleep stages, breathing patterns, heart rate, and a variety of other factors. Yet with PSG and all of these other tools at our disposal, dreams have one remarkable feature that keep them out of reach of these tools: we can't report them in real time, while we're asleep. We can utilize any of our sophisticated tools to observe the sleeping person, but the only way to know what someone is dreaming is to wake them up and ask them. Imagine designing a method for measuring your experience of dreaming. With the least invasive tools we have, we could hypothetically let you fall asleep and then repeatedly awaken you, asking whether or not you were dreaming. Would you be able to remember, and how accurately? Would you be able to report the content of your dream?

> "We are such stuff as dreams are made on, and our little life is rounded with a sleep."
>
> *– William Shakespeare, The Tempest, (IV.i.148-158)*

All of this is not to say we can't study dreams at all, nor that we can learn nothing about them. Indeed, using all of the tools above and with repetition, we have been able to generate reasonable hypotheses. We do know that most dreams happen during rapid eye movement (REM) sleep, which is defined by rapid eye movements, and decreased muscle tone on the EEG, and that most people spend about two hours per night dreaming. To quantify the most elusive task of all, interpreting dream content, systems for quantitatively studying reported dream content have been developed by a team at UC Santa Cruz.[2]

There are clear links between psychiatric illness and dreams – indeed, nightmares following trauma are among core diagnostic criteria for PTSD (post-traumatic stress disorder), and we can even reduce the frequency of nightmares in people suffering from PTSD. Prazosin is not a sleeping pill per se, but rather an anti-nightmare medication that can tune down the fight-or-flight mechanisms that are active even in sleep with some forms of PTSD.[3]

There are anecdotal and stereotyped dream experiences that are remarkably consistent across cultures and may guide us toward questions about innate learning and experience – dreams of falling, flying, being chased. Some dreams we associate in memory with anxiety – many have reported dreams of being in school or work naked, dreams of being underprepared. There are hobbyists and enthusiasts who attempt to hold on to self-awareness and experience so-called lucid dreaming, and some report being able to direct and remember their dreams.[4]

We look to dreams for insight and for inspiration. They are a wellspring for narratives that enrich our human experience and they can guide us toward decisions we didn't realize we were making. Problem solving, learning and consolidation of memories are proposed to be embedded in dreaming and sleep. The 19th Century, German chemist August Kekulé, who discovered the ring structure of benzene, reported that he visualized the structure after dreaming of a snake eating its own tail.[5]

So far, no adaptive function of dreaming has been demonstrated, yet history is rife with stories of revelatory dreams. Some dreams may be part of learning, some dreams may be reflective of our fears, some may help us learn about ourselves. There may be several different dream states that we will one day parse into specific functions that operate discretely or simultaneously. For now, the meaning and function of dreaming lie just beyond our reach.[6]

Much more amenable to study are the nuts and bolts of how we sleep, and what parts of our brains are active while we are sleeping. Falling asleep, we become drowsy, we drift through an invisible transition where we begin the cycles between the stages of sleep, and then we normally awaken equally seamlessly, ideally rested and ready to take on another day. We can observe sleep and the stages of sleep using the objective tools previously described. Our brains have a series of steps that we go through in that process of falling asleep. When the process of seamless transition from waking to sleep is misaligned and the steps don't occur in the usual order, we can experience significant problems.

There are a fascinating and well described (and fortunately treatable) set of sleep disorders called parasomnias, which occur during either REM sleep or NREM (non-REM) sleep. In NREM sleep, we see large amplitude slow waves on EEG. NREM sleep patterns are distinct from REM sleep, with deeper stages of NREM sleep (also called delta sleep) having EEG waves that are slow and large in height. Seizures or epilepsy can present in similar fashion to many parasomnias, and so, comprehensive evaluation is needed.

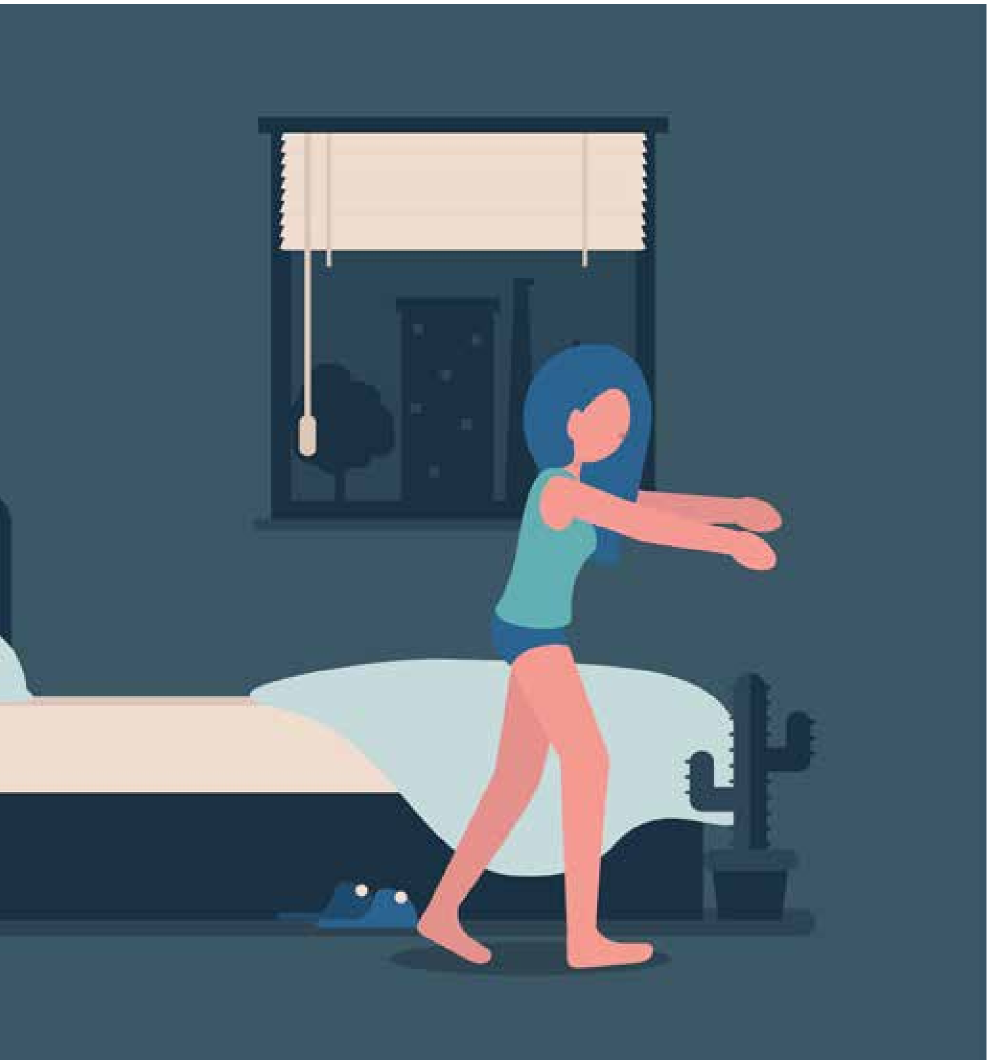
Shortly after falling asleep, and when we think most dreaming begins (about at the onset of REM sleep), there is a cellular switching mechanism located in the pons and midbrain (parts of the brainstem, the critical and very small part of the central nervous system between the brain and spinal cord), which stop you from moving, a state of relative atonia. You can still breathe, adjust your positioning and roll over (though some of those things happen during arousals when the switch is temporarily turned off, when you are partially but not completely awake), and your heart still beats as always, but volitional skeletal muscles won't move. This stops you from acting out your dreams, potentially a very dangerous situation.[7]

A few of the most common parasomnias involve problems in that switching process. If that internal switch mechanism is engaged too early while you are falling asleep, stopping you from moving volitionally, you can be awake and alert, but unable to move for a time until the rest of sleep is engaged. This REM parasomnia is called Sleep Paralysis, and the disorder associated is called Sleep Paralysis Disorder. Sleep paralysis can be addressed sometimes with medication but often does not require treatment, and a regular sleep schedule with good sleep habits are all that's needed.

Another set of parasomnias involves a problematic lack of paralysis during sleep, where the atonic switch should be engaged, but is instead allowing us to move when we shouldn't, as seen in REM-sleep behavior disorder. In REM-sleep behaviors, individuals can act out their dreams. Shouting, kicking or more complex behaviors can manifest. This poses a significant potential safety risk as someone completely asleep and unaware of their behavior can walk out of a window, walk into the road or injure others in fight/flight dreams. REM sleep behavior is commonly seen as a symptom of Parkinson's disease or similar syndromes, but can also occur on its own. Loved ones can be injured when someone with sleep behavior is shouting and striking out as sleep occurs. REM-sleep behavior disorder can be treated with a benzodiazepine such as clonazepam before bed. [8]

The fact that we are able to easily demonstrate that these behaviors occur during REM sleep provides some powerful evidence to support the hypothesis that dreaming occurs during REM sleep, especially since we see REM sleep-behavior can be complex. However, sleep behavior isn't limited to REM sleep. Some parasomnias occur during NREM sleep. These NREM parasomnias have a variety of causes and contributors, including genetic predisposition and triggers such as obstructive sleep apnea.

Most widely known among the non-REM sleep disorders is sleepwalking or somnambulation, which can be accompanied by complex behaviors, even with driving a car.



> Most widely known among the non-REM sleep disorders is sleepwalking or somnambulation, which can be accompanied by complex behaviors, even with driving a car.

Somnambulation can occur in both children and adults. Good sleep habits are a first-line treatment for non-REM sleep behaviors, but medications such as benzodiazepines or antidepressants may sometimes be needed. Another of the NREM sleep disorders, sleep-related eating disorder, may be associated with sleep medications. such as zolpidem (brand name Ambien) or eszopiclone (brand name Lunesta), and either medication can rarely lead to the curious phenomenon of awakening in the morning to find that half of the contents of the refrigerator have been eaten.

A non-REM sleep disorder or childhood is known as Sleep Terrors, a frightening thing for parents who are helping their children get through them. Night terrors are distinct from nightmares. Children will appear to be awake, but are in fact in delta NREM sleep, the deepest phase of sleep. They will open their eyes and without warning can scream and cry uncontrollably, with parents unable to console or awaken them. Children invariably have no memory of the episodes and treatment involves lots of reassurance and support for understandably traumatized parents along with a regular sleep schedule. Fortunately, night terrors don't last into adulthood and go away on their own. However, episodes of sudden night time terror are also seen in PTSD and in the setting of trauma. If a loved one is awakening with night terror-like experiences, it is important to screen for actual nightmares and trauma, or PTSD among the adolescents and adults with intellectual or developmental disabilities.[9]

Some people can be bothered by sudden, rapid muscle contractions that can occur upon falling asleep. These movements, called hypnic jerks, are sudden muscle contractions that can look like seizures, but they are a benign phenomenon that can be treated with reassurance. Some people will have periodic movements of their arms or legs that can look like seizures while they are sleeping, a disorder

> “Some dreams may be part of learning, some dreams may be reflective of our fears, some may help us learn about ourselves.

called Periodic Limb Movement Disorder, or PLMD, also called Periodic Limb Movements of Sleep or PLMS. People with PLMD will rhythmically and sometimes violently move their arms or legs while they sleep, often awakening loved ones and sometimes awakening themselves.[10]

Apart from motor function, a cognitive and sensory disconnection occurs in sleep. Our senses are muted to an extent on falling asleep, and then sight, hearing and touch come back fully online upon awakening. While we are asleep, we are not usually aware of the process and we are in a very unique and special kind of unconscious – we are not aware of the outside world but can be aroused by intense input in any sensory modality. During this period, our senses are relatively disconnected and we are free to dream.

Two mysterious parasomnias involve dysregulation of that sensory dampening. Sometimes, we can have dream intrusions into our waking world, where we can have complex hallucinations, hearing and seeing things that aren’t there while we are drifting off or awakening. When they occur during the transition to sleep, they are called hypnogogic hallucinations, and on the transition to waking. they are called hypnopompic hallucinations.

One of the most dramatically named hypnogogic parasomnias is the Exploding Head Syndrome (I promise, that’s a real thing), which is characterized by a sudden and loud sound, often described as metallic, upon falling asleep or shortly thereafter, and which is often evaluated as a potentially serious headache but which is in fact a sleep disorder.[11]

Among people with intellectual and developmental disabilities, reports of hallucinations need to be very carefully evaluated. In the general population, illnesses that are associated with hallucinations fall into potentially narrower categories than amongst people with I/DD. In addition to sleep disorders, auditory hallucinations are more commonly associated with many types of schizophrenia. Visual hallucinations are less common but are seen in vision loss (called Charles Bonnet Syndrome), in Parkinson’s Disease, and related syndromes. Tactile hallucinations are very common in many types of substance withdrawal and are seen in delirium. Olfactory (scents and odors) and gustatory (taste) hallucinations are hallmarks of many types of seizures. Evaluating complex hallucinations, or hallucinations that are experienced in more than one sensory mode, takes extra time and care.

In working with people with developmental disabilities, it is not uncommon for caregivers to seek neurologic or psychiatric evaluation when an individual with I/DD is seen to have interactions or conversations with a person who isn't there. Often, these clinic visits can lead to a diagnosis of schizophrenia or a psychotic disorder when, in fact, the experiences may not be related to a thought disorder at all.

Complex hallucinations among individuals with I/DD can be many things. Is this a fantasy being acted out and a harmless expression of an imaginary friend? Is it an expression of trauma and PTSD? Is it another medical illness? Or is it a parasomnia? It takes care and patience to discover the meaning of hallucinations in caring for someone with I/DD, and a team approach. A very careful history may be supplemented with an EEG and polysomnography in addition to some basic medical tests in order to sort it out. When a sleep disorder is suspected, the sets of disorders discussed above may assist families and caregivers to ask the same questions that we do as clinicians.

In reviewing parasomnias and sleep disorders, we can appreciate the wondrous processes operating while we are conscious and the systems operating just hidden from view while we're asleep. With the limits of our ability to quantitatively and objectively study our dreams, we may find meaning in the subjective, personal and unique stories when we remember them. We can try to observe our own dreams, and our own sleep. We can pay attention to our sleep habits and respect the investment in quality of life that can come from good sleep habits and make room for our dreams, the realm of which may be our final frontier.

> “Among people with intellectual and developmental disabilities, reports of hallucinations need to be very carefully evaluated. In the general population, illnesses that are associated with hallucinations fall into potentially narrower categories than amongst people with I/DD.

Benjamin Margolis, MD is board-certified in neurology and psychiatry, having completed the combined residency program at Brown University. He specializes in neuropsychiatric care of adults with I/DD in the New York Hudson Valley and is Senior Psychiatrist and Staff Neurologist at Access: Supports for Living. He attended medical school at the Albert Einstein College of Medicine after the postbaccalaureate premedical program at Columbia University, and holds a BFA from the School of Visual Arts in New York City. He is an active member of the American Academy of Developmental Medicine and Dentistry (AADMD) and is working to improve behavioral and mental health care of individuals with I/DD on local, state and national levels, along with serving on the Health Advisory Board for Special Olympics New York for the Strong Minds Program.

This article is included in the upcoming monograph "Sleep and Sleep Disorders in People with Disabilities" published by HELEN: The Journal of Human Exceptionality.

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SAY IT AIN'T SO, *HELEN*

By Rick Rader, MD, FAAIDD, FAADM

New visitors to *HELEN: The Journal of Human Exceptionality* don’t have to turn too many pages before they are introduced to why this magazine both promotes and endorses its namesake. HELEN was chosen because it honors the life and legacy of Helen Keller, our choice for America’s number one disability advocate. Helen not only demonstrated how a person with significant disabilities could pave the way for herself but also for others in the disability community.

1930s poster promoting eugenics from The Eugenics Society, London

Once you get past the icon that served as the inspiration for “The Miracle Worker,” you get to Helen’s other layers as an activist. Haley Moss wrote about how Keller pushed boundaries. “She was both a socialist who dedicated her life to pursuing justice for all. Keller was also a card-carrying union member, an outspoken early suffragist, and encouraged the legalization of birth control.” She also co-founded the American Civil Liberties Union and was an early supporter of the National Association for the Advancement of Colored People.

These credentials certainly have added to her renown, admiration and justification for her being inducted into the National Women’s Hall of Fame. In 1999, Keller was listed in Gallup’s Most Widely Admired People of the 20th Century. Add to those honors the many streets around the world named after her, postage stamps depicting her, along with scores of schools, hospitals, and foundations. Her birthday, June 27, is widely commemorated as Helen Keller Day.

This amazing woman also advocated for an ideology that is seen today as morally abhorrent. While it has never been a secret, it rarely is presented in any sketch of the life of Helen Keller that she promoted and supported eugenics. How could Helen Keller, a person who defied the prevailing thinking of the abilities, challenges and values of people with disabilities, support the very philosophy that proposed and promoted their annihilation?

An article by the National Institutes of Health (NIH, National Human Genome Research Institute) defined eugenics as “an immoral and pseudoscientific theory that claims it is possible to perfect people and groups through genetics and the scientific laws of inheritance. Eugenicists used an incorrect and prejudiced understanding of the work of Charles Darwin and Gregor Mendel to support the idea of ‘racial improvement.’”

In their quest for a perfect society, eugenicists labeled many people as “unfit,” including ethnic and religious minorities, people with disabilities, the urban poor, and LGBTQ individuals. Discussions of eugenics began in the late 19th century in England, then spread to other countries, especially in Germany and the United States. Most industrialized countries had organizations devoted to promoting eugenics by the end of World War I.

Keller was not alone in her interest and promotion of eugenics. Much of the research was supported by two prestigious American institutions, the Rockefeller Foundation and the Carnegie Institution. Neither of these respected organizations were backwater, unsophisticated, or radical thinking. Each is considered a bastion of progressive and humanistic thought that has made major contributions to numerous medical breakthroughs that have saved the lives of countless individuals. In addition to these two prominent academic centers, there was a long list of respected historical figures that supported the eugenics movement including Teddy Roosevelt, Alexander Graham Bell, Sir Winston Churchill, Woodrow Wilson, Clarence Darrow, George Bernard Shaw, Linus Pauling, Oliver Wendell Holmes, Jr., James Watson, and Margaret Sanger. But listing admired groups and people that supported eugenics does not justify the horrors carried out in the past.

Haben Girma, a deaf-blind lawyer and disability rights activist remarks that Keller wasn't "just" a deaf-blind inspirational figure. "Instead, she was a complicated, imperfect person as well as an activist." Catherine Kudlick, the Director of the Paul K. Longmore Institute on Disability (San Francisco State University) adds, "a lot of progressives in the 1880s, 1890s, and early 20th century were pro-eugenics. That was (at the time) considered an advanced scientific way of thinking."

In 1915, Keller published an article suggesting that birth control could help protect society from future criminals and those who are "undeserving of life."

> "How could Helen Keller, a person who defied the prevailing thinking of the abilities, challenges and values of people with disabilities, support the very philosophy that proposed and promoted the elimination of people with disabilities?

Keller biographer and historian, Kim Nielsen, noted that, "This period was short- lived and that Keller never embraced eugenic policies liked forced sterilizations and eventually moved away from her eugenicist views. Still, this detail feels shocking to modern readers, since some in the eugenics movement did advocate for the forced sterilization of those seen as genetically inferior, arguing, essentially, that people like Keller shouldn't exist."

For decades, Kelen Keller has been honored on postage stamps around the world.

As this is the *Journal of Human Exceptionality* and not the Journal of Human **Exceptions**, we cannot give a pass to Keller's support of eugenics. We are not exempting, excusing or rationalizing her stance in order to justify maintaining the name of HELEN for this publication. Instead, we are touching base with the old adage, "Don't get too close to your heroes."

Mwami-Miiro provides the rationale for this, "At some point, you'll certainly get enamored with a particular hero. They'll seem to you, from their body of work and public persona, to be the epitome of class, elegance, perfection and sophistication. You will eagerly revere them and earnestly yearn to get close to them. Their life will inspire you to better yourself, as well as impart the required clarity and conviction to do bold things plus act wisely. They you'll dare to get too close and begin to unravel the details of their personal lives until you discover the flawed upside of their persona."

The question remains, how do we view the life and legacy of Helen Keller in learning about her support of eugenics, and is she worthy of being the namesake of a journal dedicated to promoting human exceptionality? Another question kept me up for two nights when I first explored this "other" Helen; and that is, if I had known this from the start, would I have promoted HELEN to adorn the title page of this novel publication, and did I feel confident that she was the individual we wanted to celebrate each month?

I will let both the new and seasoned readers of HELEN struggle with both of those concerns. As for me, I have to review the stack of articles being submitted for the next issue of *HELEN: The Journal of Human Exceptionality*.

While we have no record of Helen Keller's struggle with her views on eugenics, we do know that, later in life, she recanted her support of this pseudo-science. She shared, "A bend in the road is not the end of the road. Unless you fail to make the turn." We are satisfied that she did make the turn.

How Individuals with ID/DD Teach Google Researchers

By Marilyn A. Ladewig, MA, CCC-SLP

Sometimes it writes something else instead but I Jeezy ration do it." Laughter quickly followed after I read this text message back to "A." I'm sure you just read that sentence over again yourself. A is a smart, articulate, and determined young woman with cerebral palsy. Her speech is difficult to understand because of a speech impairment called dysarthria, common in people with CP, stroke and Parkinson's. "Sometimes, it writes something else instead, so I'd rather just not do it" is what the text message should have transcribed. "It's so frustrating," said A. "I know," I said. "It's not your fault though. It's technology's fault. Would you like to help improve technology?" I asked. "Yes, sign me up!" she said. So off we went to a quiet area to begin her Project Euphonia recordings.

Using your voice to control technology and your surroundings is commonplace in today's world. Think of how many times, today, you used your speech to ask your smart speaker to play your favorite podcast or to increase the volume for your favorite song. You can use your voice to turn on your car, your AC before you get home, check the temperature of your refrigerator, or to ask about the weather and if it's going to rain that day. These are just everyday conveniences though. But for many in the ID/DD community, their quality of life depends on using voice-activated technology.

For millions of people around the world whose speech is difficult for others to understand, face-to-face communication can be very challenging. Using voice-activated technologies can be frustrating too. While tools like Google Home or the Google Assistant can help people call someone, adjust lighting or play a favorite song, they may not work as well for those with impaired speech. Project Euphonia is a Google Research initiative focused on helping people with atypical speech be better understood. The approach is centered on analyzing speech recordings to better train speech recognition models.

> "Using your voice to control technology and your surroundings is commonplace in today's world.

Speech impairments affect millions of individuals, limiting self-expression, vocational opportunities, and access to new technologies. Automatic speech recognition (ASR) could open doors to independence for these individuals by improving access to dictation and home automation, and ultimately facilitating more fluid real-time conversations through machine Translation. (INTERSPEECH 2021)

As a speech language pathologist working in impoverished areas of New York City with adults with developmental disabilities, Project Euphonia intrigued me back in 2019 when I had heard about it from our clinic physiatrist, Dr. Dina Nelson. Many of my patients loved using technology but often had difficulty accessing it for various reasons. They also have a history of being poorly represented when it comes to data collection for tech research. I began asking my patients if they would be interested in signing up to participate in Project Euphonia, which would involve recording someone saying some phrases out loud. Simple enough, I thought.

My patients were enthusiastic and excited by the opportunity to participate in research and to contribute to the improvement of speech recognition. I gave them the sign up info and waited. "I'm representing!" one of my clients said proudly, referring to his CP diagnosis but also his Bronx roots. Many weeks went by and hardly anyone completed the recordings. After asking several people what was stopping them from recording their speech for Google's Project Euphonia, the following difficulties began emerging: folks were unable to use their devices due to unreliable wi-fi in their government-subsidized housing; some people could not use their smartphones due to limited data plans; some folks had literacy difficulties; and some just did not have any tech literacy skills beyond using YouTube. When I explained these barriers to the Project Euphonia team, they were inspired to improve the user experience for this underrepresented group: people with developmental delays and limited resources.

That is where a partnership opportunity between one of the largest providers of services for people with developmental disabilities and one of the largest tech giants emerged. Google's AI for Social Good has teamed up with CPofNYS and ADAPT Community Network to improve speech recognition technology from the ID/DD perspective. ADAPT's comprehensive programs provide education, health, technology, residential, and recreational services to more than 20,000 individuals and families living with challenges such as autism, cerebral palsy, Down syndrome, and neuromuscular disorders. CP State is a broad-based, multi-service organization encompassing 24 Affiliates and 19,000 employees providing services and programs for more than 100,000 individuals with cerebral palsy and developmental disabilities as well as resources for families.

Over the course of three years, Project Euphonia's data collection efforts have improved and made it easier for folks with ID/DD to participate, and the individuals we serve within our "CP family" have enjoyed participating in this exciting research and helped Google realize solutions to barriers they were facing. For example, many of the individuals I work with have limited financial resources, and time is money. If time was spent recording, it could mean taking time away from a job coach or using up minutes on their pre-paid phone. So now, participation is incentivized by including a $60 gift card once the recordings are completed.

Another barrier was literacy. So the Project Euphonia team developed a text to speech feature in which the phrases would be read aloud so that the person recording can just listen and repeat. Phrases were also shortened in length, complexity, and reduced in amount needed from 1,500 down to just 300. And finally, anyone assisting the individual with completing their recordings is given a gift card as well.

Speech samples can help improve how Google understands individuals with speech impairments. In order to participate in this research initiative, you need to:

- Have access to a mobile device (Android or iOS) or a computer with a microphone.
- Be at least 18 years old.
- Be able to read or repeat English fluently.
- Have difficulties being understood by others (not only because of an accent).
- Sign up at g.co/Euphonia

Recently, Project Euphonia's research led to the creation of an app called Project Relate, a new Android app that aims to help people with non-standard speech communicate more easily with others and interact with the Google Assistant. "Project Relate can make the difference between a look of confusion and a friendly laugh of recognition," said Aubrie Lee, a brand manager at Google, whose speech is affected by muscular dystrophy. If you have a condition that makes your speech difficult to understand, and you have an Android phone, you may be able to help provide feedback on the Project Relate Android app as a trusted tester. (To express interest, please fill out our interest form at g.co/ProjectRelate, and the team will get back to you.)

Muratcan Cicek, a PhD candidate at UC Santa Cruz and summer research intern on the Euphonia team who was born with cerebral palsy, uses the Euphonia prototype app. Photo: blog.google/outreach-initiatives/accessibility/project-euphonia-1000-hours-speech-recordings/

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On Being an IMMIGRANT with Disabilities

By H. Barry Waldman, DDS, MPH, PhD
Rick Rader, MD, FAAIDD, FAADM
Steven P. Perlman, DDS, MScD, DHL (Hon)
Allen Wong, DDS, EdD, DABSCD

> “Too often invisible, too often forgotten, and too often overlooked, refugees with disabilities are among the most isolated, socially excluded and marginalized of all displaced populations.”[1]

Photo: Free Wheelchair Mission, Right At Home, Midland, MI. Rightathome.net

Workers who migrate internally or internationally, primarily move in search of better economic opportunities and access to education and health, which can improve their prospects and those of their children. Studies suggest that migrant workers with poor skills or low levels of education are exposed to a higher risk of acquiring a disability, as they often are assigned to dangerous manual labor construction and manufacturing jobs, resulting in a higher frequency of industrial accidents. Most of these low-skilled migrant workers also are usually unable to access quality health services and social security including disability benefits, compared to the resident population.[2]

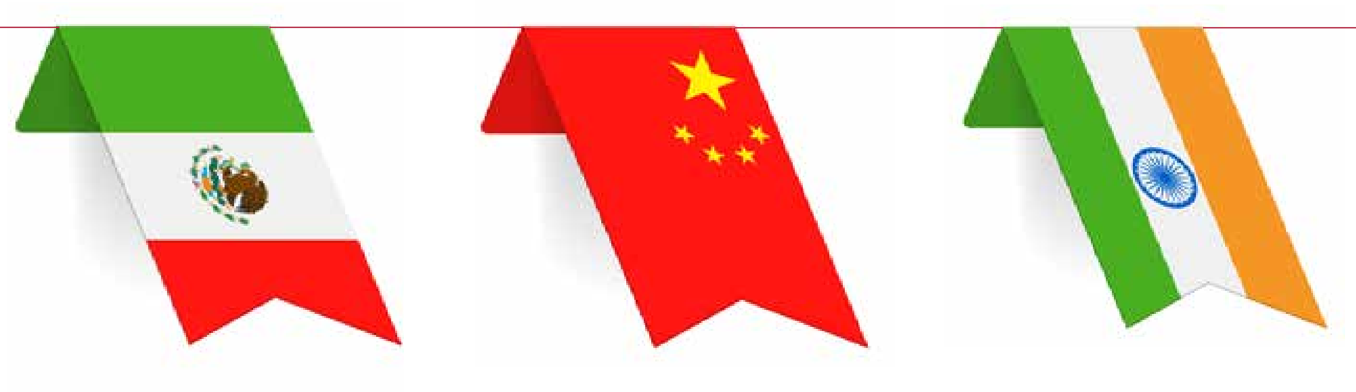
“Our (U.S.) immigration laws have always been firmly rooted in ableism. The first major immigration legislation, the Immigration Act of 1882, turned away people identified as, ‘lunatic, idiot, or any person unable to take care of himself or herself without becoming a public charge.’ Steeped in the rising capitalism that grew out of the Industrial Revolution, the public charge concept prevented immigrants whose bodies were deemed ill-suited for labor, production, and self-sufficiency from entering the U.S. In 1907, the U.S. Commissioner General of Immigration stated that, ‘**The exclusion from this country of the morally, mentally, and physically deficient is the principal object to be accomplished by the immigration laws.**’”[3] (emphasis added)

“In 2019, the Trump administration published new regulations vastly expanding the public definition, thus excluding immigrants **(especially people with disabilities)** (emphasis added) who receive any sort of government assistance from obtaining lawful status in this country.”[3]

“… disabled immigrants and their allies have battled in the courts to achieve small victories, including **access to legal representation for people with mental health disabilities in immigration court and reasonable accommodations for disabled people in immigrant detention facilities.**”[3] (emphasis added)

WORLDWIDE REFUGEES AND MIGRANTS

“Migration refers to both voluntary (e.g. migrant workers) and involuntary movement (e.g. refugees) of women and men, across geographic borders internationally or internally, with the search for a better life. According to estimates, the number of international migrants had reached 232 million globally in 2013; of the 59.5 million people forcibly displaced worldwide in 2014, about 19.5 million are refugees and 1.8 million were asylum seekers… With regards to disability, however, there is a lack of data regarding the situation and numbers of migrants with disabil-



ities… migrant workers with low skills are more vulnerable in the event of disability.”[3]

“No official international statistics exist on the global prevalence of disability within the persons on the move population; at best, there are estimates. In 2020 an estimated 12 million people in the forced displacement population were persons with disabilities, but the prevalence is likely higher.”[4]

“Worldwide, there is a severe lack of accessible housing and services for disabled refugees. A recent study by Handicap International and HelpAge estimates that people with disabilities and those who have suffered trauma and injury represent up to 30 percent of refugees.”[1]

UNITED STATES

“Immigrants with disabilities face multiple structural challenges, including discrimination, socioeconomic disadvantage, and barriers to safety net access. However, limited research discusses the prevalence of disability among nonelderly adult immigrants and the characteristics of this population...**Overall, 5.6 percent of nonelderly immigrants have a disability** (emphasis added). Disaggregation by race and ethnicity shows us that this prevalence is highest among nonelderly Black Latinx immigrants at 10.2 percent and lowest for non-Latinx Asian immigrants at 4.2 percent.”[4] (see definitions below)

DEFINITIONS

Latin America - Based in or relating to the American countries south of the U.S. where people speak Spanish and Portuguese

Latino - A native or inhabitant of Latin America or a person of Latin American origin living in the U.S.

Latina - A woman or girl who is a native or inhabitant of America or a woman or girl of Latin American origin living in the U.S.

Latinx - Designed to include those whose gender identity is fluid or nonbinary.[5]

NUMBERS AND PERCENTS

- About 3 in 10 (30.7%) immigrants with disabilities are from Mexico, making it the country of origin with the largest representation among immigrants with disabilities. (See Table 1)

- Mexico is the top birthplace among all immigrants in the US.

- 5.6% percent of immigrant adults ages 18 to 64 have a disability, and 2.3 percent have multiple types of disabilities.

- Nearly half (49.3 percent) of nonelderly immigrants with disabilities report having low family incomes (under 200 percent of the family federal poverty level).

- Ambulatory difficulty (2.7%), cognitive difficulty (1.9%), and independent-living difficulty (1.8%) are the main types of disabilities reported by immigrants.

- (10.2%) nonelderly Black Latinx immigrants reported having a disability, the highest percentage among all racial and ethnic groups.

- Non-Latinx Asian adults were the group least likely to report having a disability (4.2%).

- Roughly 1 in 3 (35.3%) immigrants with disabilities have limited English proficiency.

- About four in 10 (41.4 percent) immigrants with disabilities are employed. Three in 10 (30.0 percent) are working in service occupations, such as janitors, building cleaners, housekeeping, and personal care aides.

- One in 8 (12.7%) immigrants with disabilities reported receiving Supplemental income in the 12 months before the survey.

- Three in 10 (30.3%) noncitizens with disabilities report being uninsured at the time of the survey, while 1 in 10 (9.5%) naturalized citizens with disabilities reported being uninsured.[6]

In the U.S., a new concern has arisen: what is to happen to children with disabilities born in the country to undocumented immigrants? A spokesman for Immigration and Customs Enforcement (ICE) has said, "For parents who are ordered removed, it is their decision whether or not to relocate their children with them."[6]

COVID-19 AND DISABILITY

Due to a range of vulnerabilities such as higher incidence of poverty, overcrowded housing conditions, and high concentration in jobs where physical distancing is difficult, immigrants are at a much higher risk of COVID19 infection than those who are native native-born. Studies by OECD countries (36 countries of the Convention on the Organization for Economic Co-operation and Development) found an infection risk of immigrants that is at least twice as high as that of the native-born.[7]

Nevertheless, there are the words on the pedestal of the Statue of Liberty:

"Give me your tired, your poor,
Your huddled masses yearning to breathe free.
The wretched refuse of your teeming shore.
Send these, the homeless, tempest-tost to me.
I lift my lamp beside the golden door!"
The New Colossus 1883
Emma Lazarus

Table 1. Disability type among immigrants by age group, 2015-2019[6]

	Ages 18-34 %	Ages 35-49 %	Ages 50-64 %
DISABILITY PREVALENCE			
Any disability	**2.9**	**4.0**	**10.5**
Multiple disabilities	**1.0**	**1.4**	**4.6**
DISABILITY TYPE			
Cognitive	**1.4**	**1.4**	**3.1**
Independent difficulty	**1.0**	**1.2**	**3.5**
Vision difficulty	**0.8**	**1.1**	**2.5**
Ambulatory difficulty	**0.7**	**1.6**	**6.1**
Hearing difficulty	**0.5**	**0.8**	**2.0**
Self-care difficulty	**0.4**	**0.6**	**2.1**

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Who Knows Best What's Right f
Me or *You*?

The answer is likely both, depending on the situation. If I'm looking for a job that is fulfilling to me, while I might listen to suggestions from others, I'm really the best person to make that decision. If I'm trying to decide if the degree of heart blockage I have is best treated with medications or surgery, I'll be listening to the cardiologist for that one, for sure. Abilities and support for decision-making of people differ immensely, and with that comes varying capacities to make what most might consider "good" choices in life. Person-centered support is about helping discern the proper balance between what is important FOR a person and what is important TO a person.

For people with Intellectual and Developmental Disabilities (IDD) who are receiving supports and services, at least in my experience, the type of support provided is usually more heavily weighted on what is important FOR the person, leaving less room for the person to be able to make decisions and choices in their own lives that are important TO them that will help them lead more fulfilling lives. It's often easy to understand why, especially in the name of keeping people safe. But an interesting finding published by the Council on Quality and Leadership in 2019 showed that when people have more meaningful work and activity choices in their lives, the number of "challenging behaviors" goes down by a whopping 74 percent.[1] When we have the ability and choice to do things that are important TO each of us, we are more likely to be content with our lives and less likely to be agitated by having to do mostly what others think is right for us. It just makes sense.

Examples of things that we might consider to be "Important FOR" someone include not smoking, eating healthy, exercising, finding gainful employment, safe driving skills, regular health check-ups, and the like. Examples of things that fit into the "important TO" a person category include choices relating to what they like to eat, where they want to work, what friends they enjoy the company of, what hobbies they prefer, and even the color their room is painted.

Sometimes, there are choices that are made that may be important TO someone that are clearly not best FOR them. Smoking, excessive alcohol use, and never exercising are a few examples of these. But many people, with or without disabilities, make choices that are not always best FOR them. How do we balance supporting people with IDD to do what is good FOR them while supporting their right to make choices for themselves that may not be best FOR them? Guess what? If this has been a struggle for you as a parent, family member, or employed supporter of a person with IDD, there are actual

for Me?

By Craig Escudé, MD, FAAFP, FAADM

> Abilities and support for decision-making of people differ immensely, and with that comes varying capacities to make what most might consider “good” choices in life.

skills you can learn to help give a person positive control over their lives while assisting them in maintaining a safe lifestyle.

By participating in formal person-centered thinking training, people can learn skills to help them balance safety with choice, protection with freedom, and security with autonomy when supporting people with IDD. Even for people who might communicate in ways other than using words, there are Person-Centered Thinking skillsets that can be learned that can help supporters identify what brings someone joy in their life. Skills like Good Day/Bad Day and the Rituals and Routines help one discover what brings meaning to a person’s life in a way that works much better than just making a simple list. The Donut skill helps one to maintain focus, clarify expectations, and establish boundaries. The Relationship Map skill helps to identify what relationships are of most value to a person. The Learning Log skill helps keep track of data whenever a person has a new experience. And the 4+1 is a person-centered skill that captures four key pieces of information to guide a positive next step when helping a person problem-solve.

Person-Centered Thinking skills help those who provide support understand their roles and responsibilities to keep people moving in a direction that is more autonomous and important TO them without sacrificing what is important FOR them, like safety, security, and health. I invite you to learn more about person-centered thinking by visiting ReplacingRisk.com. It might be just the thing needed to bring balance to life for both people with IDD and those who support them.

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A Day In a (Previous) Life as a Direct Support Professional

As the sun would rise outside the group home, the evening shift would finish updating their reports as they waited for the morning staff to arrive. As the next shift trickled in, each staff member signed in, and would begin to read the previous shift's reports and briefly meet with some of the outgoing staff members to obtain updates and start the new day. Individuals were then assigned to a staff member on the new shift, with each member having an important role and responsibility in the activities of these individual's' daily living. This included getting clothes ready for the day, assisting in dressing, cooking, getting ready for school, programs, or their jobs. Trips would include those that were recreational, educational, cultural, and spiritual. Then there were those that would require a trip to their primary care physician, dentist, and other health care providers. In time, through the job, individuals weren't only your assignment but became an extended family member who you were responsible for, taking care of, looking after, and advocating on their behalf. More important, you became a part of their extended family as well. So went the day of a Direct Support Professional (DSP), something that was so familiar to me as I worked as one (though the title back then may have been different) in a previous life, during my college years, many years ago.

The PHYSICIAN - DIRECT SUPPORT PROFESSIONAL Relationship

By Vincent Siosoco, MD, MBA

What is a Direct Support Professional?

As defined by the National Alliance of Direct Support Professionals, “Direct Support Professionals (DSPs) assist people with intellectual and developmental disabilities in realizing their full potential and becoming valued and participating members of their communities. Their work is complex and goes well beyond caregiving, requiring skills including independent problem solving, decision making, behavioral assessment and prevention, medication administration, health and allied health treatment, teaching new skills, crisis prevention and intervention and more.”

History of Direct Support Professionals

In the past, DSPs functioned mainly as caregivers. However, with the growth in the field of developmental disabilities and an aging and underserved population, so did the roles and responsibilities of a DSP, which soon included supporting those individuals to lead self-directed lives when possible.

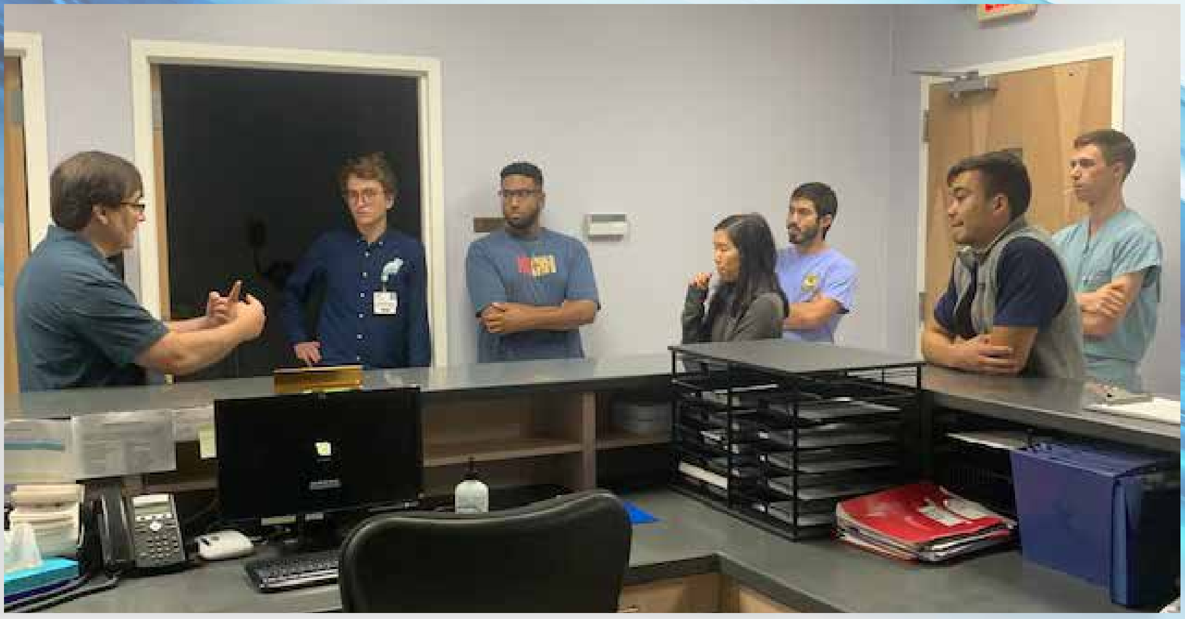
In 1996, the National Alliance for Direct Support Professionals was established. Their mission is to “Elevate the status of direct support professionals by improving practice standards, promoting system reform, and advancing their knowledge, skills and values.” As one of NADSP’s founders, John F. Kennedy, Jr. wrote “Quality is defined at the point of interaction between the staff member and the individual with a disability.” Since then, NADSP has set the standards for being a DSP, providing credentialing, education, training, and advocacy. In 2012, NADSP’s Code of Ethics was adopted by the New York State’s Office for People with Developmental Disabilities which is as follows:

1. ***Person-Centered Supports***
2. ***Promoting Physical and Emotional Well-Being***
3. ***Integrity and Responsibility***
4. ***Confidentiality***
5. ***Justice, Fairness and Equity***
6. ***Respect***
7. ***Relationships***
8. ***Self-Determination***
9. ***Advocacy***

A Day in the Life (Today) of a Physician and Direct Support Professional

As staff get settled in, the waiting room begins to buzz and fill up with patients, caregivers, and DSPs lining up to sign in and be seen by me. A lone DSP with her assigned individual sits to the side after signing in and patiently waits their turn to be seen. Many times, a fellow DSP is waiting outside in the van that brought them there, most likely double parked, due to lack of parking in the streets of NYC. The patient’s turn comes up and he and his DSP enter the examination room. After greeting him, I turn to the DSP to greet her who then begins to open up her plastic folder from the group home that they nickname, “the Grab n’ Go.” Slowly, the DSP shuffles through the folder and hands me a stack of documents that include copies of the patient’s medication list, blood pressure logs, bowel movement logs, copies of outside Specialty reports and a recent ER visit including discharge diagnoses and follow up recommendations.

The DSP hands me a Consult form where the space titled, “Reason for the Visit,” is completed for me to read, and done so on behalf of the patient who is non-verbal and can’t communicate in any way, nor comprehend his situation. Aside from the documents, the DSP gives me her own insights and experiences of being with the individual on a regular basis since the



Dr. Robert Boehm, the Medical Director of the Orange Grove Center interacting with a group of DSPs and medical students.

last visit. She's able to tell me how the Specialist's visit went the previous week, how their experience was, how it was going at the group home with staff, his roommate, and whether he's been compliant with his diet.

Many, if not most of the time, the social determinants of health information comes from these conversations. Through this information, I'm able to obtain as best a "history" as I can for the visit. After completing the physical exam, I speak with both the patient and DSP, give my recommendations, and document them on the Consult form for the DSP to bring back and share with her team at the group home and follow up on his care.

Future

It's been a long time since I worked in the role of a DSP in my college years. The role has since expanded, and their importance and value have been magnified especially through their heroic work throughout the pandemic on the front-lines. As a physician today, I see them through different eyes and as an asset in ensuring our patients receive quality healthcare. The importance of the physician-patient relationship has expanded to include that of the DSP. I look to DSPs as partners in providing the health care that is so needed for this population. Whether it's conveying information to the team or vice versa, ensuring patients receive their medications, or getting them to their next medical or dental appointment, DSPs are crucial to health care needs of these individuals.

> “
> I look to DSPs as partners in providing the health care that is so needed for this population.

I've been fortunate to know some DSPs for years now. Unfortunately, this dedicated workforce is at a critical shortage level. Their importance may not always be recognized and often not compensated in a meaningful way. Efforts are underway to address this in New York through a partnership with NY state and the NADSP to expand opportunities for DSPs.[1] Much more is needed though, to support, retain, and recruit new DSPs for the future to provide support to the individuals they serve and work alongside the physicians, dentists, nurses, and clinicians that serve those same individuals.

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King George V, Ally Bain & the “Need To Go”

ANOTHER TOOL IN THE DSP’S TOOLBOX

By Rick Rader, MD, FAAIDD, FAADM

Most British royalty leave a legacy that was exemplified by a memorable quote.

For Queen Elizabeth II it was,
“I have to be seen to be believed.”

For Prince William it was,
“As I learned from growing up, you don’t mess
with your grandmother.”

And from Prince Philip it was,
“I don’t care what kind it is, just get me a beer.”

But perhaps the most memorable of all the
Monarch’s insights is credited to King George V:
“Always go to the bathroom when you have a chance.”

My research into what potential health condition motivated him to leave that adage fell short. The closest I came was to read that he hated sitting for formal portraits and he aggravated the painters by his frequent “need to go.”

Jump cut many years later. Ally Bain desperately needed a bathroom while shopping in Chicago—and they wouldn’t let her use one in the store. This 14-year-old with Crohn’s disease used her experience to advocate for the right to use a restroom in a public place. **The result: someone with IBD or other intestinal problems, or a woman who is pregnant, now has the right to use a public toilet—and if a business doesn’t have one, the manager has to let you use the employee restroom.** Businesses in states that don’t have the law often follow the same policy now.

At least 15 U.S. states had passed versions of the law. Those states include Colorado, Connecticut, Illinois, Kentucky, Maryland, Massachusetts, Michigan, Minnesota, New York, Ohio, Oregon, Tennessee, Texas, Wisconsin, and Washington. If your state does not have a similar law, I suggest you “flash the card,” and put them on the defensive. In all probability, they will provide access to you. If they don’t, please send me the details, care of HELEN Journal, and I will follow up with those state legislators.

Yet, it still can be embarrassing to announce that you need to use the restroom or to go to the front of the line when it’s urgent. So now, there’s what’s known as a “bathroom card” you can hand an employee or those who are in front of you in line at a restaurant or event. (You can use the one below. Copy it and carry it with you.) DSPs should keep it on their phones in the event of an urgent “need.” You can also use a letter from your doctor.

Ally and her mother advocated for a law which provides access to shops and businesses that have private bathrooms. It is officially known as the Restroom Access Act, also known as Ally’s Law, to acknowledge this medical need.

Many individuals with disabilities often have acute and urgent needs to go to the bathroom. Some have difficulty expressing that need, while others have difficulty controlling the urges, and certain medical conditions manifest themselves in both urinary and fecal urgency.

DSPs need to know that this law exists and that in the event they are denied access to a bathroom they should whip out their “I Can’t Wait,” or “Bathroom Access Law” cards. It can literally save the day. It can alleviate pain, indignity, discomfort and the apprehension of leaving the group home for community activities. As the famous tagline from a large credit card company promoted, “Don’t leave home without it.”

MEDICAL
ALERT CARD

Immediate Restroom Access Required

This cardholder is suffering from the symptoms of Crohn’s disease—a chronic inflammatory bowel disease. They are physically unable to hold it in and **need a restroom immediately**.

The Restroom Access Act of 2005 requires that you make your facilities available to them. Thank you for your understanding.

janssen Immunology

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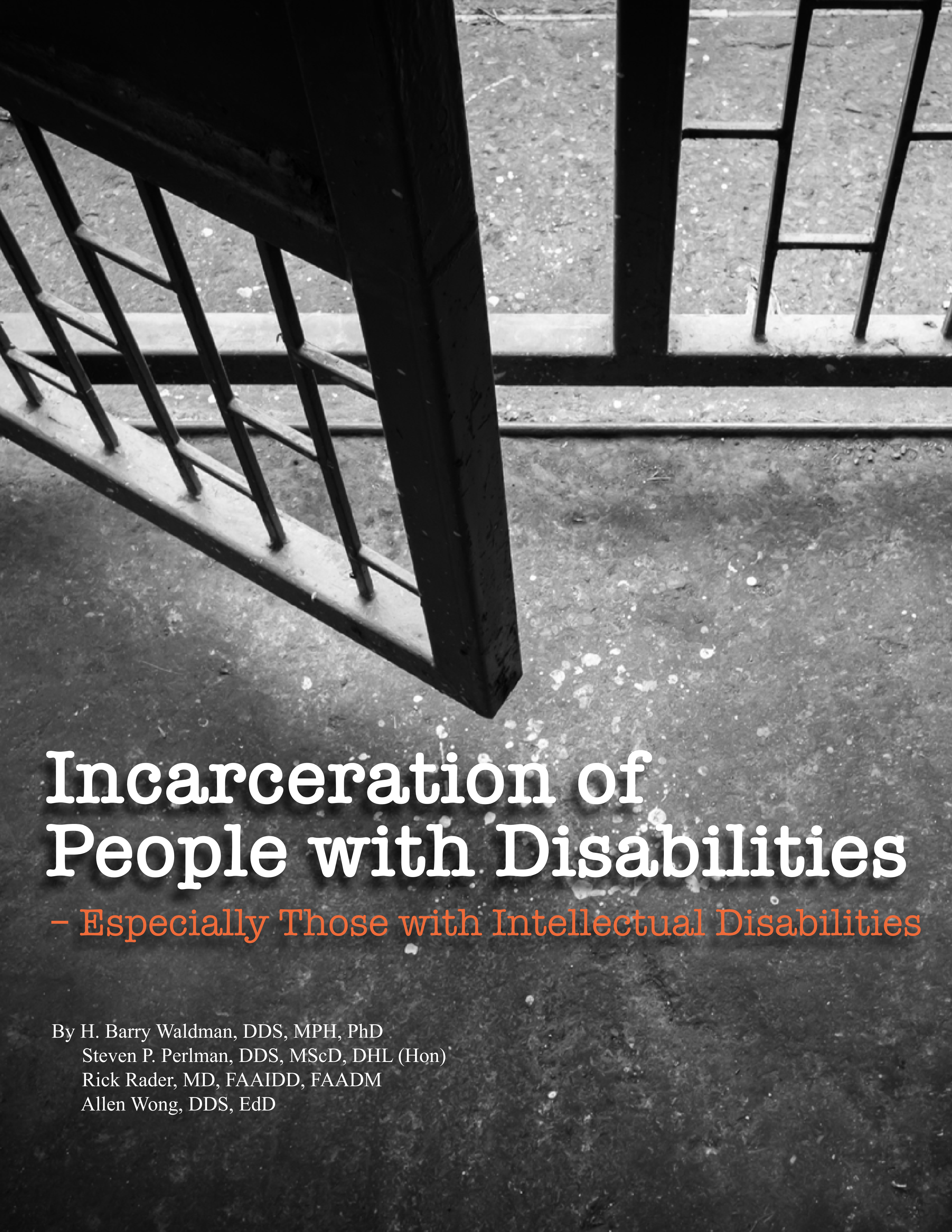


Incarceration of People with Disabilities

– Especially Those with Intellectual Disabilities

By H. Barry Waldman, DDS, MPH, PhD
Steven P. Perlman, DDS, MScD, DHL (Hon)
Rick Rader, MD, FAAIDD, FAADM
Allen Wong, DDS, EdD

From 2017 to 2019

- “Persons with disabilities were victims of 26% of all nonfatal violent crime, while accounting for about 12% of the population.
- The rate of violent victimization against persons with disabilities (46.2 per 1,000 persons age 12 or older) was almost four times the rate for persons without disabilities (12.3 per 1,000 persons).
- One in three robbery victims (33%) had at least one disability.
- Persons with cognitive disabilities had the highest rate of violent victimization (83.3 per 1,000 persons) among the disability types measured.
- Nineteen percent of rapes or sexual assaults against persons with disabilities were reported to police, compared to 36% of those against persons without disabilities.”[2]

In 2021, the Bureau of Justice Statistics, the federal agency tasked with gathering data on crime and the criminal justice system, published a report that across the entire incarcerated population, approximately 760,000 people with disabilities were living behind bars, including 550,000 people with intellectual disabilities, (who were experiencing exploitation and harsh treatment).[3]

How do people with intellectual disabilities get involved in the criminal justice system? They, as well as those with cognitive or developmental disabilities, get involved as both victims and suspects/offenders more often than individuals without disabilities.

> “The U.S. has 5% of the world’s population, but holds almost 25% of the world’s prisoners. The racial makeup in our prisons is also disproportionate.”[1]

- Children with any type of disability are 3.4 times more likely to be abused compared to children without disabilities.
- In 2008, The National Crime Victim Survey found that people with disabilities experience higher rates of violence than people without disabilities.
- People with intellectual disabilities had the highest risk of violent victimization.
- Factors such as impaired cognitive abilities and judgment, physical disabilities, insufficient adaptive behaviors, constant interactions with “protectors” who exploit them, lack of knowledge on how to protect themselves and living and working in high-risk environments increase their vulnerability to victimization.
- Once in the criminal justice system, these individuals are less likely to receive probation or parole and tend to serve longer sentences due to an inability to understand or adapt to prison rules.[4]

Some common responses from those with intellectual disabilities that may affect their ability to protect their rights include:

- Not wanting their disability to be recognized.
- Not understanding their rights but pretending to understand.
- Being overwhelmed by police presence.
- Having difficulty describing facts or details of their offense.
- Being confused about who is responsible for the crime and “confess” even though innocent.
- Not be considered as credible witnesses, even in situations where such concern is unwarranted. [5]

Note: People with intellectual disabilities are exempt from the death penalty. On June 20, 2002, the U.S. Supreme Court issued a landmark ruling prohibiting the execution of individuals with intellectual disabilities.[6]

A Great Injustice

In our institutions of incarceration, we predominantly see individuals of color, people who are African Americans, Hispanic, new immigrants, and those with disabilities who were never diagnosed or addressed. These individuals are doubly disadvantaged, if they have a multiple minority status, the school-to-prison pipeline is almost a direct event.

“People with disabilities make up something like 19 to 20 percent of population overall. Reports find that over 30 percent of people behind bars have disabilities. How can that happen?

It really happened when young people who have dyslexia or executive function disorder, don’t get the diagnosis, don’t get the accommodations that they need and they deserve in school.

They wind up getting in trouble, getting suspended, dropping out of school, not getting the accommodations they need. They’re not graduating from high school and they’re getting in trouble very early.”[7]

Is Change Possible?

“The U.S. has the highest incarceration rate in the world. Some 2.3 million men, women, and juveniles in the United States live behind bars.”[8]

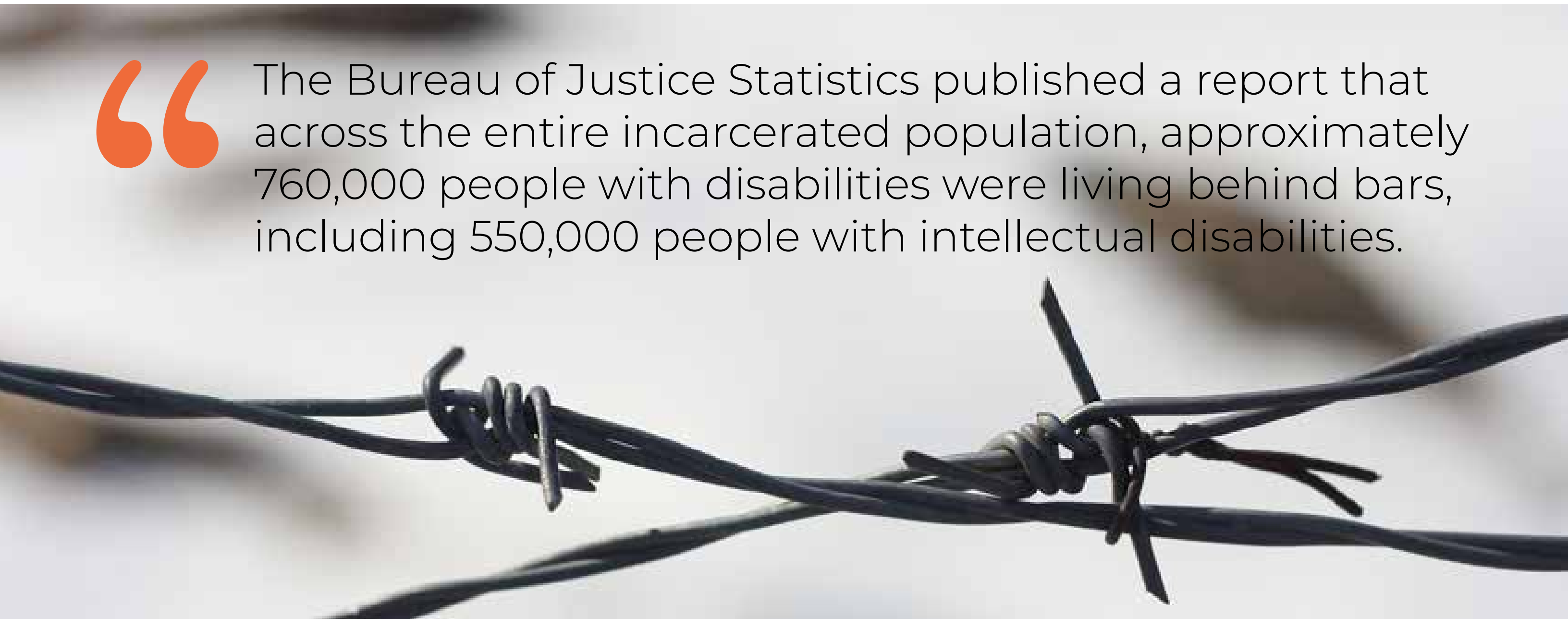
Management of inmates with disabilities is carried out by the Department of Justice, Federal Bureau of Prisons. The following steps are carried out to ensure that the Bureau properly identifies, tracks, and provides services to inmates with disabilities.

- Sufficient resources will be allocated to deliver appropriate services to inmates with disabilities.
- Staff will be provided training in order to work with inmates with disabilities.
- Developing and implementing staff training on inmates with disabilities issues.
- Advising agency leadership on the needs of inmates with disabilities.[9]

The First Step Act (FSA), passed by Congress in 2018, prioritizes increasing and improving volunteer programs nationwide. The Federal Bureau of Prisons has established programs by encouraging volunteers to assist incarcerated individuals as they reenter the general society. “Reopening across the country (following CDC guidelines) volunteers with a variety of skills will be in high demand.”[10]

The Center for American Progress issued a 2016 report, “Disabled Behind Bars,” offering promising approaches for a smooth reentry for returning citizens with disabilities, including:

- “Accessible education and training behind bars, with coordination between state departments of corrections and vocational rehabilitation.
- Discharge planning well in advance of release that takes disability and health needs into account.
- Suspension, instead of termination, of inmates’ Medicaid benefits in order to reduce interruptions in health coverage.
- Access to needed supports prior to release by leveraging the pre-release application model for health care, nutrition assistance and using a model integrating Social Security disability benefits.
- Continuity of care policies to ensure that individuals are released with enough medication to get by until they are able to see a doctor, post release.
- Physical and programmatic accessibility at halfway houses, job-training programs, and other community-based reentry services.
- Revision of the U.S. Department of Housing and Urban Development (HUD)’s definition of homelessness to expand access to supportive housing for individuals leaving residential treatment facilities.
- Reauthorization of and increased funding for the Sec-



> “The Bureau of Justice Statistics published a report that across the entire incarcerated population, approximately 760,000 people with disabilities were living behind bars, including 550,000 people with intellectual disabilities.

ond Chance Act, awarding additional points to providers that include a disability emphasis across their services.

- Increased resources for civil legal services, which play a vital role in removing barriers to employment, housing, public assistance, and supporting reentry.
- Policies that give returning citizens a fair shot at employment, housing, education and training, and other basic building blocks of economic stability after release. Supporting successful reentry for people with disabilities."[11]

Given the increasing awareness of the numbers of imprisoned individuals with disabilities, the associated costs, the rates of recidivism and government agency interactions are all essential steps in improving the future lives of imprisoned individuals with disabilities and the difficulties they face in the general public setting.

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Growing up, I did not visit the dentist for routine dental care. Often, my visits to the dental office were because of dental pain instead of preventive check-ups. When I began my journey in dentistry, I knew nothing about oral health and even less about the role of the dental hygienist. My initial interest in dentistry was simply related to esthetics, for example, having a nice smile. I wanted to pursue a career in health care but never considered dentistry as part of health. Eventually, I discovered the connection between oral health and overall health, and this is what inspired me to become a hygienist. Soon after I entered the profession, I realized there were many barriers preventing people from accessing dental care and this is what fueled my passion to pursue public health.

Photo Provided by Jeannette Diaz

How a Dental Hygienist Became a Passionate Public Health Leader

By Jeannette Diaz, MPH, MS, RDH, RDHAP

My dental hygiene training was foundational for embracing the idea of delivering oral health in a community setting. The program I attended was different from others in that we did not have our own dental hygiene clinic. Consequently, we traveled to a variety of clinics for our hands-on clinical experience. We had rotations at several county facilities, pediatric clinics, and veterans' hospitals. Additionally, we engaged with local schools, nursing homes, and group homes for people with developmental disabilities. As you can see, I grew accustomed to packing up my dental equipment and being on-the-go.

My first job as a dental hygienist was in a dental office that served children and adolescents with autism. While my dental hygiene training included various settings and caring for people with complex medical needs, I received little to no education on autism. There were times I felt nervous about working with some of my patients, especially if they were non-verbal or presenting with high dental anxiety. I now recognize these feelings stemmed from a lack of familiarity. Looking back, what helped me the most was being flexible and open to suggestions. Providing individualized care just like I would to any other person was fundamental. Learning about my patient's preferred communication style, strengths, likes, and dislikes were important for connecting and building trust. Families and caregivers were essential in helping me to better support their loved ones. The lessons learned from working in my first office were valuable and I continued to build upon these experiences.

Over the years, I went on to work in other dental offices and volunteered extensively in the community. Some of the obvious barriers to care for people with disabilities I have observed are a lack of universal design and our attitudes. Accommodating my patients' needs has meant being willing to ask questions and to be coachable. I also had to acknowledge my own bias and self-limiting beliefs. One key takeaway is the importance of identifying and reducing stress. Being intentional about getting to know my patients and celebrating their successes have resulted in positive outcomes. Although, I have been able to assist in improving the dental experience of those going to the dental office, I often wondered about those who could not reach me. Fortunately, as a hygienist licensed in California, I decided to seek additional training and became licensed as a Registered Dental Hygienist in Alternative Practice. This licensure allowed me to start my own portable dental hygiene practice and deliver in-home dental hygiene services to older adults and people with disabilities. Still, there is a need for increased awareness and collaboration to bridge the existing gaps.

> “
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> Providing individualized care just like I would to any other person was fundamental.

In 2021, I transitioned into a non-clinical position working in my state’s disabilities agency. Navigating this new role has allowed me to examine the complexities contributing to existing disparities through a new lens. As I reflect on my journey in dental hygiene, I have chosen a non-traditional path driven by the needs of others. Enhancing health equity for people with disabilities requires us to be committed and action oriented. Removing barriers involves collaboration and systems change. Our capacity for self-reflection and our willingness to have honest conversations to initiate change are essential. Most important, we must seek guidance and expertise from people with lived experiences.

Jeannette Diaz, MPH, MS, RDH, RDHAP is a keynote speaker, alternative practice dental hygienist and public health educator. She owns and operates a portable dental hygiene practice which primarily serves older adults and people with complex medical needs. Jeannette was a recipient of the 2021 Sunstar RDH Award of Distinction. Jeannette works as a dental liaison for the California Department of Developmental Services and is adjunct faculty at MCPHS Forsyth School of Dental Hygiene’s graduate program.

Challenges of Equitable Prenatal Screening

Medical leaders and academics meet to discuss education and support for patients undergoing prenatal screenings

By Stephanie Meredith

On May 13, 2022, the Joseph P. Kennedy, Jr. Foundation sponsored a Prenatal Disability Education Summit at the Johns Hopkins Medical campus. Over 50 leaders from the fields of medicine, genetics, disability advocacy, bioethics, industry, public policy, and academics convened to address the most pressing challenges in the equitable administration of prenatal testing.

This event was the first to bring together such a diverse coalition of stakeholders to discuss strategies for ensuring patients undergoing prenatal screening receive the support and information they need when learning about disabilities. Research shows that patients continue to struggle to receive adequate information about disabilities at that vulnerable moment when receiving prenatal screening results.[1] Patients want to know about the medical issues and genetics, but they also want to know what life is like for people living with these conditions and their families.[2] This is particularly vital because people with disabilities are part of an historically stigmatized population. Discussions about disabilities need to be based on accurate and up-to-date information without being biased. The stakes are high because patients can experience lasting trauma when they don’t receive needed information and support.[3]

OBJECTIVES

The primary objectives of the event were to:

1. Establish collaborative goals in the areas of public policy, organizational policies/guidelines, research, and ethical practices for the next decade to ensure that families receive accurate and up-to-date information, resources, health care, and the support they need following a diagnosis or screening results, and to help families and clinicians better understand the current outcomes for people living with disabilities.

2. Discuss best practices for both maintaining and creating relationships between the advocacy and medical communities. Additionally, we discussed strategies to educate and train medical and genetics professionals to better understand current life outcomes for people with disabilities and to incorporate that understanding into clinical practice.

MEETING FORMAT

A top priority when bringing together these diverse stakeholders, including self-advocates, family members, and professionals from 26 national organizations, was ensuring that all voices were heard and given a platform. The summit utilized the community conversation model which includes "participants as decision-makers and implementers" to improve systems and practices.[4,5] The 50 participants were divided among eight tables. The representatives from different fields at each table identified current challenges and potential solutions for one of the following topics:

1. Public policy and legislation such as Down Syndrome/Genetic Condition Information Acts, Wrongful Birth and Wrongful Life
2. Evaluating disability representation and education in organizational policies/guidelines
3. Research to improve the diagnosis experience and provision of information about conditions
4. Assessing ethical practices/disability studies perspective regarding prenatal screening and disability
5. Addressing ableism, stigma, and the needs of populations with multiple vulnerabilities: socioeconomic, racial, etc., when administering prenatal testing
6. Training for health care professionals and students about genetic conditions and disability equity
7. Developing and disseminating patient education tools about conditions
8. Ensuring best practices for delivering a diagnosis.

Participants responded to a post-summit survey, with 92% agreeing the meeting increased their understanding of different perspectives about challenges regarding the provision of prenatal disability education, and 92% also agreeing the Summit increased their vision for different strategies to address these challenges.

THEMES

Major themes that emerged during these conversations indicated that we collectively need to:

1. Conduct more research on the clinical care provided when discussing prenatal testing and a potential diagnosis, learn more about patient needs and experiences when undergoing prenatal screening and testing, and discover more information regarding health professionals' perceptions about people with disabilities.

> Research shows that patients continue to struggle to receive adequate information about disabilities at that vulnerable moment when receiving prenatal screening results.

2. Incorporate education about disabilities in broader education initiatives, including public awareness initiatives, K-12 and post-secondary curriculum, medical and genetics education curriculum, and continuing professional education.

   Curriculum and certification in disability equity should be mandated for the medical workforce and include national consensus on disability competencies and disability bias training, particularly for those presenting a diagnosis.
3. Ensure patients and providers have access to accurate and up-to-date information about genetic conditions and prenatal screening/testing. Information about conditions should include medical information, social aspects, and supports and services.
4. Develop effective strategies to increase dissemination and implementation of existing recommendations for obstetric and genetic health professionals regarding the delivery of diagnosis and screening results.
5. Address inequities in funding that contribute to disparities in the administration of prenatal testing and education about disabilities.

An overarching theme was the need for increased representation from leaders in the disability community in the development of any prenatal resources, guidelines, policies, or practices used by the medical community when discussing people with disabilities. Specifically, the representation needs to be real, meaningful, and effective—not tokenism. "Nothing about us without us." We discussed how effective representation at the outset of the process will lead to better and more inclusive research, organizational guidelines, training, and the development of resources and research.

COLLABORATIVE ACTION PLAN SUMMARY

We devised 10 action items to work toward better meeting the educational needs of patients undergoing prenatal testing and promoting equity toward people with disabilities.

1. Convene a consensus development program and a stakeholder consensus group that includes leaders in the disability community in the development of medical guidelines that impact people with disabilities and other historically marginalized populations.
2. Develop an online database to connect medical organizations and patient advocacy groups for guideline development and collaboration; sharing a racially, culturally, and disability diverse Speakers Bureau; research collaboration; and educational resource development.
3. Advocate to mandate the inclusion of disability education and equity curriculum in education for the health care workforce by identifying preferred curricula for disability educa-

tion to be implemented by decision-makers who develop medical curricula; highlighting best practices for disability education at medical conferences and publications; incorporating individuals with disabilities and families in health care education programs; sharing opportunities for health professionals to engage with the disability community, and providing implicit bias training about disabilities.

4. Create or identify an institutional home to be the clearinghouse/hub of information for providers and patients, such as Kennedy-Krieger and the National Center for Prenatal and Postnatal Resources at the Human Development Institute, to find resources for the range of conditions commonly screened, medical, and social information about conditions, and recommended support organizations.

5. Develop a collaborative policy group between patient advocacy organizations and medical organizations to work together on policy and advocacy initiatives such as research funding, funding for genetic counselling reimbursement, and funding for patient educational resources about disabilities.

6. Improve tools to help clinicians when delivering a diagnosis.

7. Work collaboratively to present at national conferences and present to member institutions.

8. Work on collaborative research projects determined through interdisciplinary conversations about research priorities.

9. Create a collaborative document outlining steps to redefine organizational priorities and principles regarding data instrumentation for collecting and conveying data about disabilities.

10. Develop templates, initiatives, and campaigns to be used for public awareness and general education purposes.

POLICY SOLUTIONS

Several action plan items can be addressed through policy solutions. According to Alex Pender, a Trustee of the Joseph P. Kennedy, Jr. Foundation, "In 2008, Senator Kennedy and Senator Brownback co-sponsored the Prenatally and Postnatally Diagnosed Condition Awareness Act which was signed into law. It was the work of two U.S. Senators who came together with different vantage points to address the concerns of parents, researchers, and scholars from a variety of disciplines. The law initially focused on Down syndrome and Congress authorized funds, but to-date no funds have been appropriated. The lack of support spurred the development of the Lettercase National Center for Prenatal and Postnatal Resources at the University of Kentucky's Human Development Institute and the long-time support by the Joseph P. Kennedy, Jr. Foundation."

Therefore, one policy solution identified at the summit was fully funding the Prenatally and Postnatally Diagnosed Awareness Act to sustain a single clearinghouse/hub of information for provider and patient resources about the social and life outcomes, medical issues, and supports and services for the range of conditions commonly included in prenatal screening. The group discussed possible funding through an educational excise tax on prenatal testing labs.

Other policy solutions could:

- Mandate disability education training for medical schools and continuing education, which would include experiences with families, information about medical and social aspects, and the history of disability rights.
- Fund research about prenatal testing experiences and attitudes of health care providers about disabilities.

CONCLUSION

As prenatal screening efforts increase, we are heading into a looming public health crisis of genetic information without a sufficient infrastructure for patient education and support. The work of this interdisciplinary team and policy leaders is essential to ensuring all stakeholders are working together to meet the needs of vulnerable families and to provide clinicians accurate and up-to-date information and training about disabilities.

Stephanie Meredith is the Director of the Lettercase National Center for Prenatal and Postnatal Resources at the University of Kentucky's Human Development Institute. She is also the author and co-author of the library of books from the National Center about Down syndrome, Turner syndrome, Jacobsen syndrome, Klinefelter syndrome, and Prader-Willi syndrome. Stephanie is a 3rd year DrPH student at Georgia State University with a focus on disability and health, and she is the mother of a 22-year-old young man with Down syndrome and two younger daughters.

The author would like to thank Dr. Harold Kleinert and Mark W. Leach, Esq., for their editorial review of her article.

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Celebrating the ADA

Challenging Health Care Inequities

For 38 years, as one of the smallest federal agencies in all of government, NCD has offered independent, nonpartisan advice to policymakers to improve the lives of people with disabilities across the United States and in our territories. The most significant of those recommendations occurred in 1988 when we advised Congress on the need for robust civil rights protections for people with disabilities and we authored the initial draft of the Americans with Disabilities Act (ADA).

On July 26, 1990, President George H.W. Bush signed the ADA into law, recognizing the decades of struggle for Americans with disabilities to achieve equality in their daily lives. The landscape of the country changed for the better as a result.

Now, 32 years after the ADA, NCD is urgently calling on Congress and the Administration to act once again – this time, to address the longstanding health disparities and healthcare bias that people with disabilities continue to experience, and at times, at the cost of their lives.

Doctors can't better treat people with whom they don't have experience. People can't get better care if they cannot get on an examination table. We cannot expect easy corrections to underservice without raising the profile on the need. We can't paint the fullest picture of the need if we're not being counted.

Comprehensive disability clinical care curriculum and training; adoption of enforceable accessible medical and diagnostic equipment standards; designation of people with disabilities as medically underserved coupled with their designation as a health disparities population; and better federal disability health care data are four pillars that will help us turn the tide.

Learn more at www.ncd.gov

Andrés J. Gallegos
Chairman, National Council on Disability

Americans with Disabilities Act
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The American Academy of Developmental Medicine & Dentistry (AADMD) is a non-profit, membership organization of interdisciplinary health professionals — including primary physicians, medical specialists, dentists, optometrists, nurses and other clinicians — committed to improving the quality of healthcare for people with intellectual & developmental disabilities (IDD). We make a difference through membership, education and advocacy.

Associate memberships available for non-clinicians as well.

Patients with IDD shouldn't have to advocate alone.

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