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ANNIVERSARY

EXCEPTIONAL PARENT

PHYSICIAN • PEOPLE

EXCEPTIONAL PARENT
MAGAZINE

MAY 2021
$7.95

INSIDE:

MOBILITY *and* PEOPLE WITH VISUAL IMPAIRMENT

EP's ANNUAL ISSUE:

MAINTAINING MOBILITY

AND:

RETURNING *to* SCHOOL POST-COVID

ALSO IN THIS ISSUE:

SELF-DRIVING CARS *and* PEOPLE WITH DISABILITIES

PLUS:

WHEN WE "MISGENDER"

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE & DENTISTRY
AADMD
Endorsed

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MAY 2021 VOLUME 51 ISSUE 5

ANNUAL MOBILITY ISSUE

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The Family and Professional Journal for the Special Needs Community
Infants • Children • Adolescents • Adults
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Assistance Animals
MOBILITY
COVER STORY
United States Military Section
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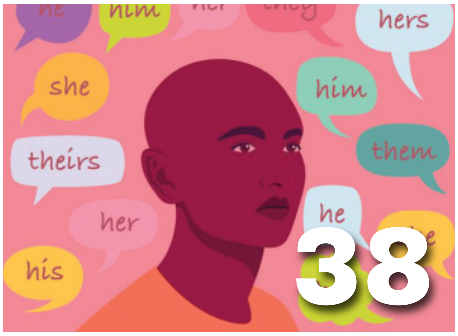
THE FINANCIAL FILE • A SPECIAL SECTION •



ON OUR COVER

Mobility is critical for functioning well and living independently, but as we age, we may experience changes to our mobility. EP's Annual Mobility Issue explores mobility from the perspective of healthy aging, as well as through articles about visual impairment and autonomous vehicles. *Coverage begins on page 18.*

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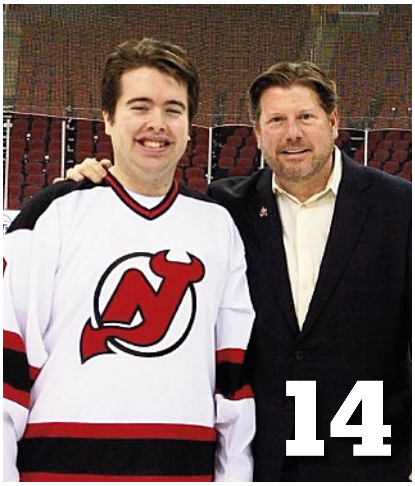
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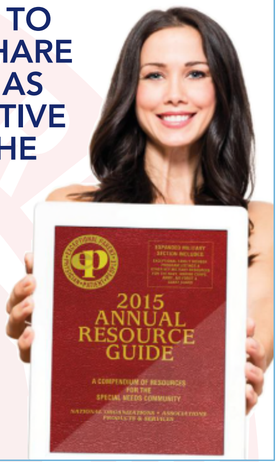

Information and Support for the Special Needs Community

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

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

The Player Pianos at Orange Grove

The Player Pianos at Orange Grove have changed the way people relate to one another. Sometimes they are partners, sometimes they are players, and sometimes they are simply an appreciative audience. But they are all connected and engaged.

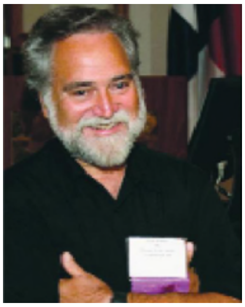
Several years ago, I found myself in the Dublin train station. There was a piano sitting in the main thoroughfare of the station. It was out in the open. It wasn't chained down. It wasn't for sale. And it wasn't sponsored by Guinness. It was just there. There and waiting for anyone to have a go at the keys.

It had a simple sign on the sheet music stand, "Play Me, I'm Yours."

And people did. All kinds of people playing all kinds of music. Some of the music even sounded like music.

It was simple, beautiful, and inspiring, and it needed to be at the Orange Grove Center, my professional digs for the past twenty-five years.

"Play Me, I'm Yours" was the creation of British artist Luke Jerram. In 2008, Jerram created the concept of installing multiple street pianos in London as a challenge to the prohibition of playing music in public places without special arrangement. It prompts members of the public to use the piano, regardless of skill and popularity. The idea was embraced worldwide and there are currently 7,177 public pianos in 114 countries. Talk about an idea that caught fire. Local artists are invited to paint, decorate, and embellish the upright pianos.



It doesn't matter what the musical skill level of the players are. You can hear Carnegie Hall-level performances and well as missed notes that are an attempt at Three Blind Mice. The public pianos adhere to the observation of American jazz pianist and composer Thelonious Monk, "The piano ain't got no wrong notes."

Around the year 1700, an Italian named Bartolomeo Cristofori was employed by Ferninando de' Medici, Grand Prince of Tuscany, as the Keeper of the Instruments. Seems at the time, the harpsichord was a difficult instrument to master and Cristofori had the idea to use hammers to strike the strings. This served as the impetus for the creation of the piano as we know it today. Cristofori had no idea that one day, his contraption would serve as a public attraction allowing strangers to stop in their tracks and contemplate how they could manipulate 88 black and white keys to create something. Something that could soothe you, arouse you, relax you, and make you tap your feet. So far as we know it, no one playing a public piano has been booed or blocked, or had to duck from hurling tomatoes.

After experiencing the Dublin public piano (and personally slapping the ivories), I went to visit my colleague, Carolyn Brown, the lead champion of the Orange Grove Center's Music Program. Carolyn is a gem who has used music to entertain, teach, and encourage individuals with intellectual and

PHOTOS PROVIDED BY RICK RADER, MD

developmental disabilities to enjoy and encourage their untapped musical talents in a variety of settings and formats.

I knew if anyone could find us our first piano it would be Carolyn. Her renown and networking in the Chattanooga music community helped to locate and acquire our first donated piano.

We assigned the decorating to Karsten Richards, an artist as well as a classroom assistant in the Orange Grove School. He created an upbeat design and we embellished it with novel attachments, including an old-fashioned microphone. No sooner was it placed in the hall with a sign that invited anyone "without skills, practice, lessons or talent" to have a go at it that it became a popular hang-out, a destination. Staff, visitors, and individuals formed spontaneous duets, ensembles, dance troupes and finger-snapping gatherings. We soon added some simple instruments, tambourines, maracas, triangles, board and sticks, and it became what it was intended to do… provide a place, a purpose and a pursuit... all in the name of joy, inclusion and attachment.

BEAUTIFUL MUSIC: Dr. Seuss *(above)* and steampunk themed pianos elicit joy, inclusion and attachment at Orange Grove.

We have since added two additional pianos with equal success and excitement.

One piano was dedicated to Dr. Seuss and was equipped with an array of squeezable animals that make sounds reminiscent of pigs, ducks and cows. While not everyone can play a piano, everyone can squeeze a pig.

Our third piano became our "steampunk" piano. This is based on the retro-futuristic machinery that was steam-generated in the 1800's and promotes the complicated machinery that was used to make things work. They are over-complicated devices that featured dials, switches, tubes, cranks and gears. Our steampunk piano was designed and executed by Dennis Wilkes, the Orange Grove resident creative artist.

Each piano has their fans and dedicated users. They all share the commonality that they are available to anyone who wants to take a few minutes respite from their routines and hammer out a tune (or something that resembles a tune). The Player Pianos at Orange Grove have changed the way people relate to one another. Sometimes they are partners, sometimes they are players, and sometimes they are simply an appreciative audience. But they are all connected and engaged.

The public pianos, which require no skills, practice, or lessons, are similar to the lives of exceptional parents. Without any practice, skills or lessons, they wake up one day and are called upon to perform. Unlike the Player Piano, there is little room in the performance of exceptional parents for hitting the wrong keys at the wrong time.

The still and idle black and white keys are like a puzzle – how to find the right ones and how to combine them to make improvements over the silence. Parents of children with special health care needs are challenged to make music, but not just background music, not nondescript elevator music, but music that causes feet to move, fingers to snap, and voices to sing.

The Orange Grove Center Player Pianos provide people with opportunities to find pleasure, without costs, without restriction, without permission, without any expectations, and without any need or provision to collect data. Wow, what a concept!

If truth be told, you don't need a 400-pound wood behemoth to offer that – you can simply start with a smile, a handshake, a back pat and an open heart; and with the reminder that "the piano ain't got no wrong notes." •

ANCORA IMPARO

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

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

WHAT'S HAPPENING

IN MEMORIAM: LINDA MESSBAUER

The American Association of Multi-Sensory Environments (AAMSE) is sad to announce that Linda Messbauer left this life on March 3, 2021.

Linda enjoyed a long and varied professional career after graduating from New York University with a master's degree in occupational therapy in 1977. She had over 30 years of experience working in the field of developmental disabilities and became one of the world's leading experts on MSE's.

During her career, Linda worked from early intervention to adult services with a variety of diagnoses. She was a Director for United Cerebral Palsy (UCP) of NYC, Rehabilitation Coordinator, and a private consultant to both public service agencies and private corporations. She had what she referred to as "the unique opportunity to work at the infamous Willowbrook State School" and developed strong beliefs about the importance of having healthy fitness with our life environments at that time. It was there Linda learned about the positive benefits of Snoezelen and set a goal to bring it from the Netherlands to America.

In 1992, Linda designed and established the first Snoezelen room in the United States in New York. She published efficacy research and became an international speaker/trainer on her therapeutic approach. Linda was a founding member of AAMSE and in 2006, started her own company named Sense-zational-Environments.

Linda's passion for teaching was obvious to those who attended her training and people commonly said she was "living before her time." Although Linda did not like hearing this, it means she provided trauma-informed therapy before it became the focus of so many of today's mental healthcare interventions. It also means she equipped healthcare communities to provide trauma-informed care before legislation was written to require it.

As the current President of AAMSE, I have provided a few of the details of Linda's accomplished life and now I would like to share the collegial dimension of Linda Messbauer that I loved best. This was the side of Linda she shared as we worked together on the AAMSE Board, in an AAMSE trainer subcommittee, and as co-presenters in AAMSE classes, or at occupational therapy conferences. I knew Linda as an intuitive therapist and friend who recognized the stress/trauma response as it exists in clients and as it exists in all of us. I knew Linda as an exceptional humanitarian and a natural scientist.

Linda was a lifelong learner and a master therapist who understood that we are all intimately connected to our life environments through our experiences and that, having good environmental fit can positively change everything about our life. She taught me and many others about her craft as she designed MSE equipment and rooms that had the power to promote the "nonlinear" transformation that was one of her favorite topics of discussion. We occasionally compared notes on how we might better communicate the new paradigm science that undergirded her innovative treatment approach.

WELL-LIVED: Linda Messbauer was one of the world's leading experts on Multi-Sensory Environments. In 1992, she designed and established the first Snoezelen room in the United States in New York.

Nonlinear change emerges like a flower grows, with some predictable and other unpredictable patterns. During the growth of a flower, there are predictable patterns as a stem unfolds and leaves or blossoms begin to form. There are also patterns that develop related to how well a flower fits in its environment, like the bending of a stem toward a ray of sunlight on otherwise shady ground. Linda accepted the openness and uncertainty of treating her clients as complex adaptive learners who change in nonlinear and only semi-predictable ways like a flower and, she achieved magnificent treatment outcomes.

Although Linda spent much of the last years of her life designing MSE's, she made it clear to all who knew her thatshe did it for the people who would be served inside them. She used MSE's to bless the lives of people of all ages with extreme challenging behaviors and people in the late lifespan with dementia. She used MSE's to bless the lives of people in palliative care and even ones transitioning from this earthly life.

Linda, we at AAMSE like to think that you were blessed by the presence of someone trained to provide the peaceful transition from this earthly life for you, that you gave to so many others.

– With love,
Janice Ryan, OTD
AAMSE President 2021.

PHOTO PROVIDED BY JANICE RYAN, OTD

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- 2 each spray bottles triggers
- 1 box of disposable gloves
- 1 pack of 12 machine washable microfiber cloths
- 2 each disposable, non-medical face masks
- 1 pack disposable dusting sheets
- Directions, tips and more.

Clean Smart

www.bantec.store/products/bantec-disinfecting-kit

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WHAT'S HAPPENING

WEBINAR SERIES: VACCINES FOR CAREGIVERS AND PERSONAL CARE ASSISTANTS

A webinar intended for anyone interested in learning more about caregivers and PCAs and COVID-19 vaccines within the disability community.

Wednesday, May 12, 2021, 3:00 PM to 4:00 PM ET

www.eventbrite.com/e/covid-19-vaccines-for-caregivers-and-personal-care-assistants-pca-tickets-149933907353

Early registration is required. Registration closes 1 hour before the live webinar begins.

Vaccines are an important tool for slowing the spread of COVID-19, especially for caregivers and personal care assistants (PCA) working with people with disabilities. Unfortunately, the COVID-19 pandemic continues to affect direct care and support of people with disabilities.

This past year has brought heightened anxiety and uncertain feelings to many people's lives. However, following recommendations, including getting the COVID-19 vaccine, are important steps towards keeping the virus at bay.

This webinar will explore the considerations of COVID-19 vaccines for caregivers and PCAs within the disability community. Presenters, many who are caregivers and PCAs themselves, will share their COVID-19 vaccine experiences and why they chose to get vaccinated. Webinar participants will receive tips, resources, and guidance for COVID-19 vaccinations as we collectively navigate this challenging time.

Target Audience

This is an introductory-intermediate level webinar intended for anyone interested in learning more about caregivers and personal care assistants (PCA) and COVID-19 vaccines within the disability community.

Getting 'Back to Normal'
Is Going to Take **All of Our Tools**

If we use all the tools we have, we stand the best chance of getting our families, communities, schools, and workplaces "back to normal" sooner:

Get vaccinated.

Wear a mask.

Stay 6 feet from others, and avoid crowds.

Wash hands often.

www.cdc.gov/coronavirus/vaccines

12/09/20

WHAT'S HAPPENING

Registration

Register for this free webinar and please share with your colleagues, clients, and community. Webinars are presented through Zoom. Captions and American Sign Language will be available. All webinars are recorded and the archive, transcript, accessible presentation, as well as additional handouts will be made available within one week of the live webinar.

Learning Objectives :

Upon completion of this webinar participants will be able to:

1. *Describe 3 important guidelines to follow before and after getting a COVID-19 vaccine.*
2. *Identify 3 positive impacts of COVID-19 vaccines for caregivers and personal care assistants.*
3. *Identify 3 resources on COVID-19 vaccines for supporting caregivers and personal care assistants*

More Webinars

Stay tuned for information about another upcoming webinar in the series: FAQs About COVID-19 Vaccines that People with Disabilities Should Consider. Check out all of the COVID-19 Accessible Resources!

Visit the microsite hosted by Georgia Tech at **https://cidi.gatech.edu/covid** for additional resources and archived webinars, including new videos: *Wear a Mask the Right Way* (**https://www.youtube.com/watch?v=16LZgIrVeFo**) and *Stay Six Feet Away from People* (**https://www.youtube.com/watch?v=DApFg1tpuCs**).

For questions about this webinar or if you would like more information about the COVID-19 Accessible Materials for People with Disabilities Project, please contact **training@gatfl.gatech.edu**.

This webinar series is made possible due to funding from the CDC Foundation along with technical assistance from the Centers for Disease Control and Prevention.

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Georgia Tech Center for Inclusive Design and Innovation

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AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE & DENTISTRY

Differences Between Women and Men with Disabilities

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

"Attitudinal barriers confronting (women) with disabilities are constructed out of myths and stereotypes, many of which harken back to the superstitions of ancient history that regarded the disabled as evil, possessed by the devil, or being punished for past evils." [1] (Note: These ancient evil perceptions were to some degree associated with the fact that healthy women would periodically experience unexplained vaginal bleeding with no symptoms of illness.)

There is a well-known expression "**men are from Mars; women are from Venus.**" It was promoted to describe the distinct differences in the emotions, perspective, outlook and behavior of males and females. While there are several moving parts in the contrasts, there is one that has not been widely considered as a major divider, and that is a disabling condition. The question of how disabilities, abilities, ableism, inclusion and personhood can bring men and women together or serve to promote confusion, misunderstanding and separatism is worth examining.

WORLDWIDE

> *"For far too long, women and girls with disabilities have been invisible, both to the advocates of women's rights and of disability rights, and this has increased their vulnerability. Women and girls with disabilities… are likely to experience the 'double discrimination,' which includes the gender-based violence, abuse and marginalization. As a result, women with disabilities often must confront additional disadvantages even in comparison to men with disabilities and the women without disabilities."* [2] (UN Report)

GENDER AND DISABILITY

The 2011 World Report on Disability indicates that the female disability prevalence rate is 19.2 percent, whereas it is 12 percent for men.

- *The global literacy rate is as low as three per cent for all adults with disabilities, and one per cent for women with disabilities.*
- *Although all persons with disabilities face barriers to employment, men with disabilities have been found to be almost twice as likely to be employed as women with disabilities.*
- *Women and girls with disabilities experience higher rates of gender-based violence, sexual abuse, neglect, maltreatment and exploitation than women and girls without disabilities and are three times more likely to experience gender-based violence compared to non-disabled women.* [2,3]

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY

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

CONTRIBUTING FACTORS

Actions and initiatives often do not give adequate attention to the gender gap in disability. For example:

- *Double discrimination faced by women and girls with disabilities are often compounded by other factors such as being minorities, indigenous people, refugees, persons living with HIV and AIDS and as older people.*
- *Women and girls with disabilities are discriminated differently from men, i.e.: women are at higher risk of sexual violence, forced sterilization and forced abortion.*
- *Lack of empowerment and capacity development of women and girls with disabilities, limits their future leadership and participation in the decision making in political, economic and social spheres.*

As a result of aging and longer life expectancy of women, the number of women with disabilities is likely to be become higher in many populations than the number of men with disabilities. Many older women who are disabled may lack access to services/support. [2,3]

In all countries, they face significantly more difficulties – in both public and private sectors – in attaining the social determinants of health, such as adequate housing, health, education, vocational training and employment. They also experience inequality in hiring, promotion rates and pay for equal work, access to training and retraining, credit and other productive resources, and rarely participate in economic decision making.

CONTRIBUTING FACTORS

About 36 million women in the U.S. have disabilities – and the number is rapidly growing. About 44% of those aged 65 years or older are living with a disability. The most common cause of disability for women is arthritis or rheumatism. [4]

The percentage of the disability population that is male is lower in metropolitan counties (47.5%) and higher in micropolitan (49.8%) and noncore counties (50.7%). However, for women, the percentage of the disability population is higher in metropolitan (52.5%) and lower in micropolitan (50.2%) and noncore counties (49.3%). [5]

About 1 in 4 of all women have experienced contact sexual violence, physical violence, and/or stalking by an intimate partner during their lifetime. Research also has shown that women with a disability are more likely to experience intimate partner violence (IPV) than those without a disability. Women with a disability were significantly more likely to report experiencing each form of IPV measures which included rape, sexual violence, stalking, psychological aggression, and control of reproductive or sexual health. [6]

In 2006, disability-associated health care expenditures accounted for 26.7% of all health care expenditures for adults residing in the United States and totaled $397.8 billion, with state expenditures ranging from $598 million in Wyoming to $40.1 billion in New York. Of the national total:

- *Medicare paid $118.9 billion.*
- *Medicaid paid $161.1 billion.*
- *Non-public sources paid $117.8 billion.*

In part, the magnitude of disability-associated health care expenditures stemmed from the high prevalence of disability among the adult population, with 18.2% of all adults reporting a limitation in some way in at least one activity because of physical, mental, or emotional problems. [7]

WOMAN'S WORK: In all countries, women experience inequality in hiring, promotion rates and pay for equal work, access to training and retraining, credit and other productive resources, and rarely participate in economic decision making.

> *"Women with disabilities have historically been neglected by those concerned with issues of disability as well as the feminist movement. It is only within the last decade that serious attempts have been made to identify and understand the forces shaping their lives. These attempts have mainly focused on understanding how being female and having a disability interacts and how women with disabilities view their experiences."* [8]

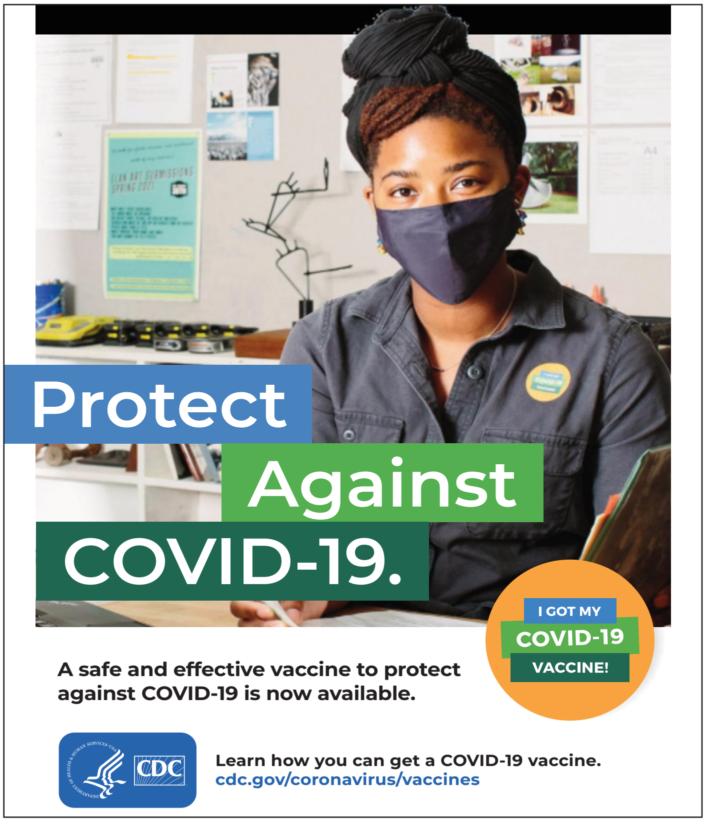
According to a Bureau of Statistics report, the unemployment rate among women with disabilities is 9.4%, whereas it is 4% for those without disabilities. That means women with disabilities are more than twice as likely to be unemployed than are their non-disabled counterparts. (Note: The group with the next highest rate is Black Americans, at 6.8%.) The Bureau also shows that only 28% of women with disabilities were employed in 2018, compared to 68.6% of women without disabilities. Meanwhile, 31.7% of men with disabilities were employed. [9]

WE KNOW THE NUMBERS, WHAT'S NEXT?

"Unwittingly or not, mainstream feminists have long been excluding their disabled sisters in their activism. Often times this is due to the lack of empathy or awareness. Non-disabled feminists are too frequently unaware of their own privilege and ableism when it comes to the intersection of feminism and disability. Financial freedom is ultimately one of the critical components for a woman, or anyone, to live independently. It is often the driving force for someone to get out of an abusive relationship, for example. This is all the reasons why feminist movements must include women with disabilities." [9]

REALITIES TO BE ADDRESSED – AN EXTENDED SERIES OF STEPS MUST BE INCLUDED

Gender Violence: Women with disabilities experience high rates of violence, both at the hands of family members and of personal assistants.



Access to Justice: Access to justice for any historically marginalized group is essential in order to address wrongs and seek remedies.

Access to Rehabilitation Services: Services that do exist are very often inaccessible or unavailable to women and girls.

Access to Essential Health Care: Women and girls with and without disabilities also face major barriers related to their right to basic health care.

Right to Sexual and Reproductive Health Care: Women with mental and physical disabilities must fight to participate in decisions about their health care.[10] One area of women's health that has not received enough attention is the oral-systemic relationship which includes specific women's issues, such as: menstruation, pregnancy, menopausal osteoporosis, and oral contraception. [11]

Right to Marry and Form a Family: Women with disabilities also face limitations on their rights to marry and have a family.

Education and Literacy: Disability discrimination combined with cultural and gender discrimination sometimes keeps women and girls with disabilities out of school.

Workplace Discrimination: Often, the labor market does not adequately accommodate women with disabilities. Not being able to fulfill job requirements or that reasonable accommodation will be extensive and costly.

Adequate Standard of Living: When women are most valued for their productive and reproductive capacities, women with a disability face even greater discrimination.

Women with disabilities: Must take on leadership roles. [10]

IF NOT BY **YOU**, THEN **WHO**? •

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BOOK EXCERPT

LIVE LIKE SEAN

Important Life Lessons from My Special-Needs Son

BY TJ NELLIGAN

[*Editor's Note: This is the first chapter of Live Like Sean, a memoir written by TJ Nelligan upon the sudden passing of his 29-year-old Sean on Father's Day 2019.*]

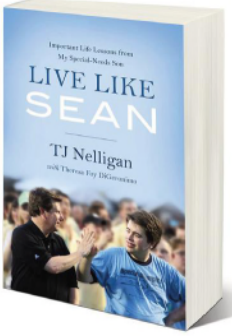
“Gratitude? I didn't have much of that in my young adult life before Sean came into it. As an entrepreneur in a capitalistic society, I always wanted more. I spent days wondering how big I could grow my company. How many more employees could I hire? When a life is built on working 10 to 12 hours a day, there isn't much time to think about gratitude.

Then Sean was born. When his mom, Maggie, and I realized that he was a “special-needs” child, I can tell you that my heart was still not filled with gratitude. I felt many emotions. Anger and fear were at the top of the list, but gratitude was nowhere to be found.

The extent of Sean's developmental issues revealed itself slowly. After his birth, we took home what appeared to be a perfect, healthy newborn. There was no indication of the trouble ahead. The first sign appeared at six months; changing his diaper, we noticed that sometimes his leg would spasm. We took him to the hospital, where the doctors said it was probably just a muscle spasm. But I knew that it was not.

I spent the night in the hospital beside his crib with a video camcorder, waiting to record a spasm. When I showed the tape to the doctor the next morning, he confirmed that Sean was having seizures. That's when the rounds of testing and doctor visits and anti-seizure medications began.

After the initial shock and hurt, I think my emotions just froze. At first, I got through each day by putting my life with Sean in a compartment called denial. I told myself: *It's going to be fine. It's going to be fine. It's going to be fine.*



Title: **Live Like Sean: Important Life Lessons from My Special-Needs Son**

Author: **TJ Nelligan** with **Theresa Foy DiGeronimo**

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The End Of Denial

When Sean was about two-years-old and his developmental delays were becoming more alarming, a friend recommended that we see the world's top neurologist, a professor at Columbia University College of Physicians and Surgeons and a pioneer in the field of child neurology. It took a long time to get an appointment, so I was able to stay in my world of denial a bit longer. But finally, on a Saturday morning, Maggie, my mother, Sean, and I went to the doctor's home office in Englewood, New Jersey.

As we sat in the waiting room, I was silent. The doctor had already received the test results from Sean's other doctors. He knew about the seizures and had the EEG test results. Now, he wanted to talk with Sean and observe him. He watched how Sean walked, how he talked, how he reacted to various stimuli. He spent a good hour with Sean, and then it was time for the verdict.

Sean stayed in the waiting room with his grandma while Maggie and I went into the office. The doctor was behind his desk while we sat on the other side feeling frightened and insecure. I looked at all the diplomas lining the walls and the shelves of the books the doctor had authored, knowing this should make me feel confident and at ease, but all I felt was scared. The fact that this man was so well respected in his field meant that I was going to have to accept what he said, and I had a sinking feeling that he wasn't about to give us good news.

It was immediately clear to me that the doctor knew what he was doing. He was all about the facts. But he had no bedside manner. There was no softening the sharp edges. He had seen children like Sean many, many times in his career. It seemed that, to him, Sean was just another intellectually and developmentally damaged child. He matter-of-factly explained that Sean would never live a normal or average life. He would never fit into mainstream society. He would definitely not be able to graduate high school or go to college and, most likely, wouldn't be able to have a meaningful job.

IMAGES COURTESY TJ NELLIGAN/GREENLEAF BOOK GROUP PRESS

As we left the office, I don’t remember exactly what I said to the doctor in response to this news, but I’m absolutely sure it wasn’t “thanks.”

On the ride home, we couldn’t speak. Even little Sean sat still. What words were there to accept what we had just heard? What words were there to explain how we were feeling? Those words don’t exist. We were all silent.

That night, after Maggie put Sean to bed, I went into his room and shut the door behind me. I gripped the edge of the crib and looked down on my sleeping child. I asked him, “How are we going to do this? And then I cried and cried.

LIVES IMPACTED: TJ Nelligan and son Sean; Sean taught those around him simple but important lessons: to be happy, accepting, and have a pure love of life.

Finally, I had to accept that there was a problem, and Sean *wasn’t* going to be okay. I couldn’t keep Sean in a neat little compartment in my mind anymore. There would be no more, “work goes here, marriage goes here, Sean goes here.”

That was when I felt the true burden of disappointment. Getting this news about Sean shattered my expectations. It was the death of my dreams for my first child. My son. Sean would not be the starting pitcher for his baseball team. He would not play a musical instrument in the school band. He would not get married and have children of his own. The Nelligan name would not move on through him to the next generation. He would not live a life that I thought he deserved. My heart was broken. What did I have to be thankful for?

> **“Getting this news about Sean shattered my expectations. It was the death of my dreams for my first child. He would not live a life that I thought he deserved. My heart was broken. What did I have to be thankful for?”**

Although no parent wants a child to have a difficult life, and many of my feeling were rooted in this worry about what would happen to Sean, I admit that some of my emotions were coming from my fear about how he was going to negatively impact *my* future. Raising a child with multiple disabilities set the parents on a long, winding journey with no road map or even a clear destination. There are years and years of nonstop visits to doctors, speech therapists, occupational therapists, and physical therapists. Then there are tests, evaluations, hospitalizations, medications. And so much more. I don’t remember even once thinking “thank you.”

I realize now that gratitude is the foundation of happiness. The two go together. And perhaps that is why in the first decade of Sean’s life, I had neither. I was too busy protecting him. In doing so, I’m sure I lost many opportunities to enjoy him and thank God for him, but at that point I couldn’t do anything else. It was like carrying around an egg that could drop and break at any wrong turn. His mom and I felt that we needed to protect him from getting hurt – physically and emotionally. We wanted to protect him from hurting himself, not only when he stumbled, which was often, but also from people who might say mean things to him, from an educational establishment that didn’t understand his needs, from a world where he wasn’t “normal.”

This was going to be a hard and long road – for me. At that time, I couldn’t see the shattered dreams were not Sean’s dreams. He was not angry or disappointed. He seemed quite happy to be alive. Every day was a great day. Going through the thousands of pictures of Sean while preparing for his memorial, his sister Meghan noticed that he wore his wide and wonderful smile in every single photo. (Well, except for the one in which his sister Moira is using him to practice her hair-cutting skills.) He always carried himself through each day with joy and, yes, with a sense of gratitude that astounded and confused me.

I felt confused, probably, because I never really knew what gratitude meant until Sean taught it to me. That is ironic because I’m sure that people who didn’t know Sean would look at him and think, “What does he have to be thankful for?” However, his sense of gratitude wasn’t the result of an easy, protected life – not at all. Sean suffered emotionally and physically through those early years: the years of physical therapy, when he was learning to walk with leg braces that hurt so much. The years of speech therapy, when he lived with the frustration of wanting to communicate but being unable to form words or write letters. The years of confusion, when he seemed to be hesitant to be involved with the world around him.

A Change of Perspective

Despite his struggles Sean was able to have so many of the things we all want to have and should take the time to be grateful for: kind and helpful teachers, good friends, loving sisters, a supportive family, a passion for sports and music. Those things filled Sean’s heart with happiness, and his ability to truly appreciate the important things in life showed me how my own lack of gratitude for these same things made happiness impossible.

I couldn’t feel grateful because I believed that I was somehow entitled to a “normal” child. But Sean didn’t feel this way, so his gratitude came easily. It wasn’t until years later that I saw in his happiness and his acceptance of the life he had been given that the neurologist was 100 percent right. Sean was never going to be average. He was exceptional.

Sean stood tall and rose above the doctor's dire predictions because he never felt gypped. He didn't feel like he was missing out on anything. He had no expectations or sense of entitlement. From his perspective, he wasn't cheated by life or given less than anyone else. In fact, he seemed to know what he was given more than most of us will ever have. He entered every room with his signature smile, making everyone he met feel special. He didn't apologize for himself. He didn't want to hide so no one would know he was "different." As he grew into his teens, Sean walked around like he was the mayor, saying hello to everyone, giving out hugs, handshakes, and compliments: "I like your new haircut." "Those are nice shoes." "You are a good friend." He would say these things with confidence that was unimaginable a decade earlier. He showed his gratitude for everything in life by living that life with joy, contentment, and acceptance. And I was learning to do the same.

Live Like Sean

I have begun this book with a lesson about gratitude because, in my experience, it is the hardest lesson to learn. It takes the longest to learn. And yet it is the most enduring and is now the foundation of my happiness. I am truly grateful for every memory – the painful and the joyful – that highlights Sean's relentless efforts to show me a way through my own heartbreak and to have gratitude for our life together.

I realize that each special-needs child is unique, just as all children are. Some are naturally happy; some are not. Some are outgoing; some are not. And so on. Therefore, I don't pretend that just because Sean was able to wake each day with an attitude of gratitude that this is the case for all children. However, I do believe that all special-needs children offer us the opportunity to see the world with new eyes – their eyes. It is the world in which they live; they know no other. For Sean, that gratitude grew out of his ability to live a happy and meaningful life with his family and friends (and to see the Giants win the Super Bowl.)

For me, learning how to be grateful didn't happen like a bolt of lightning. I had to absorb that lesson over time. Learning to live like Sean began when I slowly began to see the world from his point of view, rather than through my own lens of disappointment.

If you are a family member of a special-needs child, I don't expect that after reading this you will feel suddenly grateful. But there are some things you can begin to do:

- Give yourself the chance to actively and consciously look for moments to say "thank you."
- Let those small moments contribute to growing the hope for future happiness.

I hope that together, we can move through each of the upcoming chapters from a place of despair to a place touched by gratitude.

> **"I don't pretend that just because Sean was able to wake each day with an attitude of gratitude that this is the case for all children. However, I do believe that all special-needs children offer us the opportunity to see the world with new eyes – their eyes."**

I can finally answer the question that I had asked a million times: Why would God give me this child? Twenty-nine years later, I know the answer. I had a lot to learn about living a good life built on a foundation of gratitude, and I needed Sean to teach me. For this gift, I am forever grateful.

(Published with Author's Permission) •

ABOUT THE AUTHOR:

An entrepreneur, advocate, and former Chairman & CEO of the Special Olympics 2014 USA Games, TJ Nelligan is a man of action who has made it his life's mission to benefit others. Inspired after his son's sudden passing, Nelligan authored *Live Like Sean: Important Life Lessons from My Special-Needs Son*. An Amazon Best Seller, *Live Like Sean* provides a first-person perspective of seeing the world through the eyes of his special-needs son, who taught the world more than it could ever teach him.

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

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COVER STORY

Mobility

MAINTAINING MOBILITY

AND PREVENTING DISABILITY ARE KEY TO LIVING INDEPENDENTLY AS WE AGE

FROM THE NATIONAL INSTITUTE ON AGING

Many people worry about not being able to move around as well when they get older. They fear they won't be able to continue their favorite activities, visit their favorite places, or even keep up with everyday tasks. Mobility — the ability to move or walk freely and easily — is critical for functioning well and living independently. As we age, we may experience changes to our mobility. There are many reasons for these changes, including changes in gait (how we walk), balance, and physical strength.

All of these can increase the number and severity of falls and make it harder for older adults to go out and visit with friends and family and continue doing their activities independently. Older adults who lose their mobility are less likely to remain living at home; have higher rates of disease, disability, hospitalization, and death; and have poorer quality of life.

Researchers are working on this issue because it's not only a matter of physical health, but also the social and emotional well-being of older adults.

NIA-supported researchers are identifying risk factors for physical disability and developing and testing ways to prevent or reverse loss of mobility to help older adults maintain independence. For exam-

WALK THE WALK: With increased mobility, older adults can move around and perform daily activities more easily and safely and continue to live as independently as possible.

ple, long-running observational studies, such as the Women's Health and Aging Study II (https://coah.jhu.edu/research/projects/whas_ii.html) and the Health, Aging, and Body Composition Study, (https://healthabc.nia.nih.gov) examine functional decline and how it differs by race and sex.

"One of our goals is to continue focusing on research aimed at maintaining independence in mobility in old age," said Sergei Romashkan, M.D., Ph.D., chief of the NIA Division of Geriatrics and Clinical Gerontology Clinical Trials Branch.

Older adults often lose physical function after hospitalization or falls, or if they have movement-related disorders such as Parkinson's disease. People who have lost physical function may face difficulty with activities of daily living (ADLs), such as eating, bathing, dressing, or using the bathroom without aid. Researchers are investigating ways to improve physical function following hospitalization that would enable older adults to recover and "age in place" (www.nia.nih.gov/health/aging-place-growing-older-home) independently at home, avoiding costly institutional care.

A lack of physical activity or exercise can also make it more likely that a person will experience loss of mobility as they age. The increasing incidence of sedentarism (sitting too much) is a growing health concern: Too many older adults don't get enough physical activity and spend too much time sitting daily. Researchers are studying this issue and working to establish a foundation of scientific evidence on the topic to inform public health guidelines on how to interrupt sedentary behavior in ways that support healthy aging. In addition, some interventional studies have found positive results of physical activity and exercise on continued mobility. Following are examples of promising NIA-funded studies in this area.

> ***"Older adults who lose their mobility are less likely to remain living at home; have higher rates of disease, disability, hospitalization, and death; and have poorer quality of life."***

HOME IMPROVEMENTS TO HELP OLDER ADULTS REMAIN FUNCTIONAL

Two-thirds of older adults discharged from the hospital each year face new difficulty with ADLs, including walking, and are unable to take care of themselves when they leave the hospital. Most adults strongly prefer to live at home, but many have difficulty taking care of themselves after a hospitalization. To date, there has been little research on integrated health and housing interventions to improve physical function.

The NIA-supported CAPABLE (Community Aging in Place, Advancing Better Living for Elders: https://nursing.jhu.edu/faculty_research/research/projects/capable) home-based intervention program has been shown to be effective in increasing mobility, functionality, and the capacity to "age in place" for low-income older adults. CAPABLE evolved from another NIA-funded study, ABLE (Advancing Better Living for Elders: https://pubmed.ncbi.nlm.nih.gov/25429187), which provided older adults home-based occupational and physical therapy, along with home modifications to reduce physical disability and improve quality of life.

CAPABLE combines evidence-based nursing, occupational therapy, and handy worker services to help older adults function at home and prevent costly institutional care. Participants enrolled in the program include low-income older adults age 65 or older with mild or no cognitive impairment who had trouble with at least one ADL. Over five months, participants work with a registered nurse who visits their home three to four times and an occupational therapist who visits four to six times. Services include management of pain, medication, and depressive symptoms. CAPABLE also features a home repair service person who performs up to $1,300 in home repairs, modifications, and may purchase assistive devices. Participants don't have to pay for services or repairs, rather, the costs of about $3,000 per person are covered by the program's organization.

Using motivational interviewing and action planning techniques, the older adult takes the lead in working with the team to identify barriers to overcome and specific functional goals they would like to achieve (such as walking down stairs, bathing or cooking independently, or reducing pain). This participant-led approach is a major factor in the program's success.

For example, if the participant wants to bathe safely but fears slipping and falling in the tub, the nurse might partner with the participant to identify issues that can affect balance, like pain or muscle weakness; the occupational therapist could teach strengthening and balance exercises and ways to get in and out of the tub safely; and home repair technicians could install safety features such as grab bars and nonslip treads.

Each service builds on the others by increasing the participants' capacity to function at home. This may decrease hospitalization and nursing home stays by improving medication management, prob-

MOVE IT OR LOSE IT: The increasing incidence of sedentarism is a growing health concern: Too many older adults don't get enough physical activity. Researchers are studying how to interrupt sedentary behavior in ways that support healthy aging.

lem-solving ability, strength, balance, mobility, nutrition, and home safety, while decreasing isolation, depression, and fall risk.

"The program is tailored to the participants' specific goals that fit their priorities, and we're not prescriptive about what those goals are," said Sarah Szanton, Ph.D., R.N., A.N.P., F.A.A.N., who developed the program and is director of the Center on Innovative Care in Aging at the Johns Hopkins School of Nursing in Baltimore. "In addition, we're addressing participants and their environments at the same time, which is a motivating factor."

John Hancock, 63, of Baltimore, used a walker due to a knee injury, and wasn't able to get in his bathtub for months without assistance. It also was difficult to walk up and down the stairs in his home, which he shares with his daughter and grandson. He learned about the CAPABLE program through The Johns Hopkins Hospital, where he had recently been hospitalized.

"When they called to ask if they could come out to see if I qualified for the program and if I was willing to participate, I said 'yes,'" said Hancock. "My 'yes' became victorious."

Through CAPABLE, Hancock worked with an occupational therapist, a nurse, and a home repair service person to create a plan to get him moving more freely again and living more independently. The team carried out the plan through calls and home visits every three to four weeks to brainstorm a new goal on each visit. He learned how to do exercises so he could get up from the floor and move his legs. A railing and a bath chair were installed so Hancock could get in and out of his bathtub on his own. And after six months, he ditched his walker for a cane and didn't have to undergo knee surgery. Going up and down stairs was no longer a chore.

"I previously couldn't do anything for myself," said Hancock. "I was a broken person and didn't know where to turn. Now I am able to do things on my own, so I don't have to depend on my daughter too much. I couldn't move, and now my body is more flexible. The people from CAPABLE take the time to guide you on how to do everything the right way. Their major concern was finding out what my needs were and getting me proper care. This program opened a door for me."

Studies show CAPABLE improves function and lowers hospitalization and nursing home rates. When starting the program, participants in one study (https://pubmed.ncbi.nlm.nih.gov/27605633) had difficulty with an average of 3.9 of 8 ADLs, which decreased to two ADLs after five months. In addition, 65% reported less difficulty in performing instrumental ADLs (such as shopping, cooking, paying bills, or taking medications) and more than 50% said their depressive symptoms improved. According to another study, older adults who participated in the program had a 30% drop in reporting difficulties or needing assistance in performing ADLs compared with those who only had social visits from a research assistant after five months. Participants were also more likely to report that the program made their life easier, made their home safer, kept them living at home, helped them take care of themselves, and helped them gain confidence in managing daily challenges.

In addition to improving quality of life, CAPABLE is cost-effective. According to a Centers for Medicare and Medicaid Services evaluation of its CAPABLE demonstration project, the program costs $2,825 per participant on average and yields a 7-to-1 return on investment of $22,000 in reduced Medicare costs over two years. The lower costs were due to associated reductions in both inpatient and outpatient expenditures, such as hospital stays and readmissions.

"Sometimes just inexpensive things working all together can make a big difference in improving patients' functionality," said Szanton.

To date, about 2,500 older adults have participated in CAPABLE, which is currently offered through 31 organizations in 15 states (https://nursing.jhu.edu/faculty_research/research/projects/capable/where-we-work.html) in the United States and Australia. Facilitators include health care systems, Area Agencies on Aging, Medicare Advantage health plans, state and local governments, insurance companies, skilled nursing facilities, nursing homes, Veterans Administration centers, home health care agencies, and health care and housing nonprofits such as Meals on Wheels and Habitat for Humanity.

Although CAPABLE is not currently covered as a Medicare benefit, this could change in the future. Szanton would like to see Medicare's annual wellness visit periodically occurring at a patient's home so their environment could be observed in relation to tasks such as bathing, dressing, or grooming. CAPABLE is also being tested by the Visiting Nurse Service of New York in an NIA-supported study (https://projectreporter.nih.gov/project_info_description.cfm?aid=9366493&icde=48643050) of people who lost physical function after recent hospitalizations.

"We will continue to address what matters to older adults and leverage person-environment strengths, including family," said Szanton.

HOW PHYSICAL ACTIVITY CAN PREVENT MAJOR MOBILITY DISABILITY

Many studies have shown that regular exercise improves physical performance. But little is known about whether exercise can actually help prevent major mobility disability, defined as the inability to walk a quarter of a mile, or four blocks. Researchers sought to learn more about this connection through the Lifestyle Interventions and Independence for Elders (LIFE) (https://pubmed.ncbi.nlm.nih.gov/32105353/) study, which they designed to assess whether a long-term structured physical activity program was more effective than a health education program in reducing the risk of major mobility disability in older adults who lived a sedentary lifestyle.

> ***"We need to get more older adults exercising. The biggest challenge is being able to motivate people to exercise and then sustain physical activity, especially if they have mobility and functional problems."***

For the study, 1,635 participants aged 70 to 89 were randomly assigned to a structured, moderate-intensity physical activity program, or to a health education program of workshops on topics relevant to older adults. Racially and ethnically diverse participants at high risk for disability were recruited from eight university centers across the U.S. in urban, suburban, and rural communities. They had some evidence of impaired function at baseline but were all able to walk 400 meters (about a quarter of a mile) in a screening test. The objective of the intervention was to maintain this ability and prevent loss of ability to walk this distance.

The physical activity intervention involved walking (with a goal of 150 minutes a week), strength training, including the use of ankle weights, flexibility, and balance training and included attending instructor-led exercise classes twice a week at a center and a home-based activity three to four times per week for two years. The health education program included weekly health education workshops on topics such as travel safety, health screenings, and nutrition, along with five to 10 minutes of instructor-led upper body stretching and flexibility exercises for the first 26 weeks, and then monthly sessions for the remainder of the study. Participants were assessed every six months at clinic visits for physical activity measures, including the ability to walk 400 meters.

Participation in the program was measured by attendance at sessions and by questionnaires in which participants recorded the number of hours per week they were physically active. In addition, participants' activity was recorded for one week during each year of the trial through an accelerometer, a small belt device that measures physical activity.

Results showed that over 2.6 years, the physical activity program reduced the risk of major mobility disability by 18% compared with the health education program. These findings suggest that older adults who are vulnerable to disability can benefit from physical activity.

"The intervention was not only effective in preventing mobility disability, but it was also cost-effective," said Marco Pahor, M.D., principal investigator of the LIFE study, director of the Institute on Aging at the University of Florida in Gainesville, and chair of aging and geriatric research at the university's College of Medicine. "Those who started with the poorest function benefitted the most from the physical activity program. The results also showed perceived benefits in walking speed and physical performance scores," meaning people felt they were getting benefits beyond what the study could actually measure.

This groundbreaking study was the largest and longest lasting randomized controlled trial ever conducted on physical activity in older adults. Its findings have shaped several U.S. and international recommendations for physical activity in older adults, including the U.S. Department of Health and Human Services' Physical Activity Guidelines for Americans (https://health.gov/sites/default/files/2019-09/Physical_Activity_Guidelines_2nd_edition.pdf).

"Beyond the specific findings on exercise, the study showed that older adults, who are traditionally excluded from large clinical trials, can be successfully recruited and retained for clinical studies, and will adhere to an exercise program," said Jack M. Guralnik, M.D., Ph.D., co-principal investigator for the study and a professor in the Department of Epidemiology and Public Health, Division of Gerontology, at the University of Maryland School of Medicine in Baltimore. Guralnik was formerly chief of the NIA's Laboratory of Epidemiology, Demography, and Biometry.

"We've come a long way in the last 20 to 25 years, but a lot more can be done," said Guralnik. "We need to get more older adults exercising. The biggest challenge is being able to motivate people to exercise and then sustain physical activity, especially if they have mobility and functional problems."

TAKING A STAND AGAINST SITTING

Many older adults struggle to engage in health-enhancing physical activity and spend, on average, between nine and 13 hours a day sitting.

There is little scientific evidence on how best to interrupt long periods of sedentary behavior, and few studies that have focused on physical activity interventions to reduce such behavior. Still, interventions focused on standing have been shown to reduce sedentary behavior up to two hours per day. Also, epidemiological studies have shown associations between self-reported sedentary behavior and increased risks of death and metabolic outcomes, but very few prospective studies have used objective measures of sedentary behavior.

After an NIA summer workshop series to address the lack of scientific evidence in this area, researchers at the University of California, San Diego (UCSD) launched the Sedentary Time and Aging Research (STAR) (riseforhealth.ucsd.edu) program. The goal is to provide more rigorous and comprehensive evidence on how to interrupt extended sitting time and its consequences for healthy aging in premenopausal women. The research includes investigating novel mechanisms important for healthy aging, as well as investigating behaviors such as standing and brief sit-to-stand transitions that expend little energy but engage muscles, improve postural blood flow, and may impact physical functioning in older adults.

> ***“Many older adults struggle to engage in health-enhancing physical activity and spend, on average, between nine and 13 hours a day sitting.”***

This ongoing, five-year program includes three protocols:

- *A randomized crossover clinical trial* of postmenopausal women to test whether different interruptions to prolonged sitting improve metabolism*
- *A randomized controlled trial designed to assess ways of interrupting sitting in overweight, postmenopausal women*
- *A prospective study using machine-generated algorithms to assess how sitting, standing, moving from sitting to standing, and physical activity are related to biomarkers (biological indicators of disease) of healthy aging, physical functioning, and mortality*

In one study (https://pubmed.ncbi.nlm.nih.gov/32063113), researchers at UCSD are partnering with the American Heart Association to assess three-month changes in sitting time, standing time, physical activity, and blood pressure among 250 postmenopausal Latino women aged 55 and older who are obese, spend at least eight hours a day sitting, and have increased risk for cardiovascular disease. The women wear an accelerometer on their thigh, which is a small device that measures physical activities such as lying, sitting, standing, and stepping. Preliminary findings show that the association between sitting behavior and increased fasting glucose may be higher in Latino women than non-Latino women.

“There is epidemiological evidence that sitting too much has negative effects on diabetes, mortality, and physical function (https://pubmed.ncbi.nlm.nih.gov/32646435), and is associated with adverse outcomes,” said John Bellettiere, Ph.D., M.P.H., M.A., an assistant professor of epidemiology in the Department of Family Medicine and Public Health and co-director of the epidemiology curriculum of the Clinical Research Enhancement through Supplemental Training (CREST Program) at UCSD. “In our most recent research (https://academic.oup.com/biomedgerontology/advance-article/doi/10.1093/gerona/glaa227/5920919), we have seen reduced mortality risk among older women – 37% – with higher rates of standing. The lower mortality risk was observed just by replacing sitting with standing still – our participants did not have to move around, although when they did walk around while standing, the reduction in mortality risk was even larger.”

In another 12-week study to assess the effect of changes in standing and the number of sit-to-stand transitions on physical, emotional, and cognitive functioning, sedentary postmenopausal women age 55 and older are randomly assigned to various combinations of these interventions:

- *One-on-one, in-person, and phone health coaching sessions aimed at goal setting, implementing strategies, overcoming barriers, and relapse prevention*
- *An activity monitor to measure sitting and standing time and to enable health coaches to provide feedback and assist in developing an action plan*
- *Tools to prompt standing or sit-to-stand transitions such as wearable wrist devices, standing desks or tables, mechanical and/or electronic timers, or access to mobile apps or computer programs*

These interventions are aimed at reducing daily sitting time and increasing the daily number of brief sit-to-stand transitions.

“We are studying the immediate, short- and long-term effects of breaking up sitting with short periods of standing or taking brief walks during the day,” said Andrea Z. LaCroix, Ph.D., Distinguished Professor of Epidemiology and principal investigator of STAR at UCSD. “The results of these studies will provide evidence on how often we need to get up from sitting to improve how our bodies function across a spectrum of health indicators from circulation to measures of metabolism in our blood, and most importantly to maintaining mobility and extending the healthy part of longevity.”

In the future, research on maintaining independence in older adults might include more practical studies to evaluate strategies for implementation in real-world settings and interdisciplinary studies on mobility that integrate expertise in muscle physiology and neurology, according to Romashkan. It might also include developing more meaningful quality-of-life measures and intervention studies to determine how specific mechanisms of physical activity enhance mobility function in older adults, which could lead to improved exercise interventions or alternative treatments, he added.

And with increased mobility, older adults can move around and perform daily activities more easily and safely and continue to live as independently as possible. •

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*A type of clinical trial in which all participants receive the same two or more treatments, but the order in which they receive them depends on the group to which they are randomly assigned.

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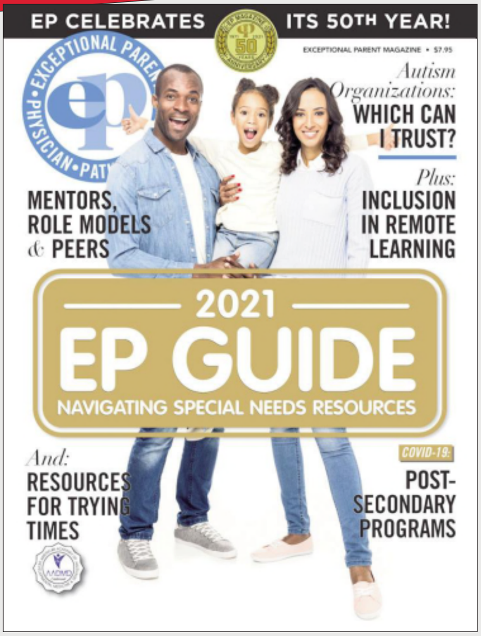

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Mobility

TRAINS, APPS & SEEING-EYE DOGS

WORKING AROUND MOBILITY CHALLENGES WITH THE RIGHT ATTITUDE AND TOOLS

AN EP MAGAZINE INTERVIEW

EP Magazine recently had a lively, informative and upbeat conversation with Christina Llanes Mabalot, a frequent editorial contributor to this publication, motivational speaker, educator, and advocate for the special needs community. Christina, who is based in South Carolina, is completely blind from aniridia. When she was younger, she could still discern figures from afar, but the health of her eyes would deteriorate through the years. Along the way, she's purposely and fearlessly faced new situations to arm herself for similar ones in the future. It's all about learning, and attitude, and it's been quite a ride.

Christina has always insisted on being independent and living her life to the fullest. She earned her Master's in Education, specializing in Early Intervention for the Blind. She received Educational Leadership training through the Hilton-Perkins International Program in Massachusetts, then worked as consultant for programs for the VI Helen Keller International. She has championed Inclusive Education, Early Intervention, Capability Building and Disability Sensitivity programs.

In our interview, Christina revealed some of her interesting experiences as a person who is blind. She also shared several tips and sage advice regarding mobility for others who are blind or visually impaired.

EP Magazine: You have aniridia as do your three siblings and daughter. When you were younger you were visually impaired, but later in life, you became completely blind. Please describe your mobility challenges during your youth, when you were in grade school and high school.

Christina Llanes Mabalot: Doctors declared me and my siblings to be legally blind. The doctors were even surprised that we could see at all because of our unique eye anatomy. Like my siblings, I was extremely near-sighted. In general, I could perceive big objects and structures from a relatively farther distance. Smaller objects and details were difficult to see, unless I stood next to them or brought my face close. Lighting, and whether the setting was outdoors or indoors, affected my perception. Mostly, it was easier to navigate in the daytime, or with the right amount and quality of light.

When outdoors, the intense sunlight blurred my vision. People with aniridia are advised to protect their eyes from the sun's glare. Doctors advised us to wear shades with ultra violet protection, but I hated wearing them because they "shaded" my vision. Squinting my eyes was my best defense from the sun. I could not read road signs unless the letters were huge, or I was next to them. I often slipped on the floor before I could read the warning signs for "wet floor" or "wet paint". When taking public transportation (in Metro Manila, in the Philippines), I had to wait for the vehicle to stop and ask drivers or passengers about their destination till I found the right vehicle. I would do a rollcall to eventually find my ride.

It was more challenging to navigate poorly lit, unfamiliar areas. I would stumble or bump into furniture and fixtures, and sometimes run into walls. This was especially true when objects were painted with dark colors, or when their color blended with the area's overall color. Climbing steps was easier for me than going down. My depth perception was very limited. I remember falling down stairs or steps when walking and engaged in conversation, or when not focused on navigation. Poor visual recognition of people was another issue.

EP Magazine: **When things worsened, while in college, you still took public transportation. Talk about your experiences, getting around at this time of your life. Did you make sure you were always with someone else when you were out in public? Did you use a cane?**

CLM: I didn't know it was time to use a cane, although my residual vision was fast deteriorating. I had to take two rides going to and from university. The first was a jeepney that took me from our house to Taft Avenue (in Manila), a major, busy highway. Sometimes, I would ask one of our domestic helpers to get me on the jeep or on the bus to get to school, but those times were rare. The Metro buses to the University of the Philippines passed by the bus stop every 15 minutes. I had little trouble identifying them by their bright blue and white color.

Travelling back home was the test for perseverance, however. It was often too dark by then, and I only had light perception. I walked to the bus stop via my mental vision. One night, I rammed my head into a lamp post and acquired a big lump at the center of my forehead, like a unicorn's horn. Forget about identifying the vehicles' colors, for the glare of headlights blinded me. Sometimes, friends helped me get a ride, but when by myself, I usually asked assistance from the other passengers at the bus stop. When there was no one around, it was time to pray because it became a hit-or-miss, lost-and-found situation for me. I remember times when I hopped on wrong buses and ended up in unfamiliar areas. When I couldn't find assistance from other people, I ended up taking a cab home. When in dire straits, I'd go in an establishment for a pay phone and call my parents for help.

EP Magazine: **Describe your mobility experiences around some of the busiest cities in the world, at the time you were in New York and Massachusetts to fulfill work for your Helen Keller Foundation grant during the 1990s. How did you navigate the streets or subways, for instance? How did the Helen Keller group help with resources?**

HELP AROUND THE HOUSE: Christina Llanes Mabalot uses multiple tech tools in her home including Amazon's Alexa, which controls lights, thermostat, vacuum cleaner, Ring doorbell and the security system while providing notifications and online shopping.

CLM: Helen Keller International (HKI) provided all I needed for mobility and travel. They equipped me with Orientation and Mobility training. By then, I was finally able to use my cane efficiently. HKI also gave me vouchers for cab fares to get from one point to another. For my trainings, I was based in Watertown, Massachusetts, home of the Perkins School for the Blind. My favorite spot to visit was Harvard Square, where I'd walk around shopping, or hang around just for the adventure. I always ended up getting lost, but I'd just hop on a cab to take me back to the dormitory. Eventually, I gained friends who enjoyed window shopping, so I often rode with them. We visited tourist and scenic spots, including Salem.

To report to the HQ, I'd travel from Massachusetts to New York via train. Usually, an HKI staff waited for me at the station to guide me to the office. However, there were times when I had to travel alone. It is important to note that streets in New York are logically structured, thus easy for a blind person to know exactly where to go. The problem was the sidewalks are strewn with vendors, merchandise, animals, and God knows what! Worse, some people were mean. It was a time when society was not all that sensitive to people with special needs. "Can't they see that I'm tripping and falling with my cane to get through?" I'd often ask myself. One time, I think I toppled a man's showcase of goods as I swung my cane. The vendor was livid. I explained how I was sorry, and to understand that I can't see. I heard him walking closer to me. Threatened, I unintentionally hit him with my cane. He called the police. Thank God they were on my side.

PHOTO PROVIDED BY CHRISTINA LLANES MABALOT

EP Magazine: When you were in your 40's, you had to have your eyes enucleated. What was the reason for this move? Then describe the process of learning to get around all over again.

CLM: I was already totally blind when we decided to have my eyes enucleated (medical term for removing eyeballs). During that time, I was dealing with so much pain due to glaucoma, (high ocular pressure), and I had to take several medications and eyedrops to maintain a normal pressure. On top of this, my left eye bulged so badly while my right shrank. I was a perfect picture of asymmetry for kids learning the concept. Blindness, intense headaches, plus my negative self-image, these all led my husband and I to decide to have my eyes removed. Doctors advised that I should do it one eye at a time, but I refused. "If I were to go under the knife, it would be only one time... or I might change my mind for the second surgery," I reasoned.

> **"IT'S MOSTLY EASIER FOR PEOPLE BORN WITH RESIDUAL VISION TO LEARN ORIENTATION AND MOBILITY. EVEN IF THEY EVENTUALLY LOST THEIR VISION, THE ADJUSTMENT WOULD NOT BE TOO DIFFICULT, IN TERMS OF SKILLS."**

The time I had to relearn navigating was when I realized I lost my vision. I remembered having residual light perception, which somewhat helped me in navigating. Over a period of time, I found myself bumping into objects, even in my own home, because I was following what I thought to be light. My thinking was, there should be daylight from windows or from lamps, so I moved accordingly. But my calculations turned out wrong. Curious, I asked my husband one day, "Should I turn off the light?" My husband replied, "Are you joking? The lights are off because it's bedtime." There was a perennial glare in my sight which I thought to be light, like in the old days. Little did I realize that I had completely lost vision. What remained was either phantom vision or something else. Peers who are blind see either pitch black or cloudy white or, in weird cases, a combination of both. With the perennial glare, I had to get used to not mistaking that for lights, and then move without relying on any light perception.

EP Magazine: Would you say it's easier for someone who was born blind to learn to navigate public spaces – or someone who started out with residual vision, then became completely blind later in life? Please elaborate.

CLM: From experiences in the blind community, it's mostly easier for people born with residual vision to learn orientation and mobility. They already possess some kind of visual concept of the environment they're in. So, even if they eventually lost their vision, the adjustment would not be too difficult, in terms of skills.

The real issue to contend with is really depression... grieving the loss of vision, which is usually a tougher battle for those who were sighted and lost their vision. I'm currently coaching a pastor in his 60's who is suffering from macular degeneration. He was diagnosed with the condition when he suddenly became blind in one eye. Earlier, he had tunnel vision, which was still some form of residual vision, which helped him navigate. Then he lost that remaining vision too. He's mostly grieving loss of the ability to drive. On a good day, it's easy to coach him navigation skills because he possessed a mental picture of his environment. He's continued to preach since he's committed most verses to memory. However, more are the days when he can't be engaged because of depression. He's been rushed to the emergency room a few times due to anxiety attacks.

Orienting someone born blind is more challenging only because that person needs to understand his environment. Sometimes words can't paint a picture of something which has never been perceived.

EP Magazine: What advice can you give to someone who will be going through what you've gone through – where you started in life as someone with some vision, then went on to become completely blind? What should they prepare themselves for in terms of learning to get around and be as independent as possible, in navigating both the home as well as the world outside?

CLM: Attitude is everything. Regardless of what happens, a positive outlook always saves the day. It's healthy to grieve any loss, including vision, but to grieve all your life is as bad as death itself. Once one has accepted blindness and decides a career making use of one's talents and abilities, the next step is to set up how to pursue it, including travel. Weigh options for getting to work. If working remotely isn't an option, but one really wants to pursue a certain career, then sign up for trainings...or consider owning a guide dog. It's not easy, but maintain the desire to be independent so one won't be discouraged to learn. A person who is blind can't always depend on others for help and support. There may come a time for one to have to travel alone.

Enjoy the support, but also learn how do travel on your own. It doesn't hurt to be prepared for the worst. I have a co-worker who's totally blind. His parents always took him to and from work. One day, his father became ill and his mother had to care for him. He ended up not going to work for days because he was too afraid to take an Uber. I myself was afraid the first time I had to take public transportation to school. I was used to being driven, or taking the school bus. But, as I said, there'll always be that one time when support won't be available. So, I had to do it afraid. After the first time, I decided to train myself not to be afraid, so I consistently commuted until I got used to it.

One should also possess the humility to ask for assistance when needed. It may be difficult sometimes, especially if one has had a bad experience with a mean, sighted person, but don't take it personally. Develop a thick skin. Requesting assistance may be your lifeline.

EP Magazine: What do you know of modern technology and its role in supporting people who are blind or visually impaired, in helping them navigate public spaces? Can you mention specific tech tools that will make it easier for them to be as independent as possible? Which of these tech tools are you using in the house? When you're outside the home?

CLM: In the house: Alexa – controls lights, thermostat, air frier, "Dbot" vacuum cleaner, ring doorbell, and security system. It can also provide notifications, and do anything Amazon-related, even online shopping. Having a smart phone with accessibility is a must. With the text-to-speech features, your phone can read the map, even on a walking mode, so that you know where to go. Waze – it's is like Google maps, only better.

"Seeing AI" is an artificial intelligence app developed by Microsoft (for IOS) narrates the world around you. It describes what's in front of the phone camera like short text, documents, products, people, scenes, currency, light, color and currency. "Be My Eyes" is an app which contacts a volunteer for support, in real time.

EP Magazine: Your daughter, Jem, is visually impaired and thinking of starting a life and career in another country. What have you two discussed about independence and getting around in an unfamiliar environment?

CLM: I've advised her to study the map of places she's visiting, and the safest way to get there. To make sure she's figured out where she can eat, buy groceries, etc. Use all resources out there, like apps, websites connections across all platforms that will help her gain knowledge to be independent. This is why we made sure she has data connection wherever she goes. A pocket wi-fi has served her needs.

Another thing, network – as it's always beneficial to know a lot of people, so when she was abroad recently, we hooked her up with friends... Take a foldable cane (that would fit in her purse) everywhere she goes, in case she needs it... Rule #1 – I told her, don't fall in love in a foreign country. Falling in love might take away her independence. The biggest thing was to equip her to be online. When you get lonely, call Mama. When I asked her, she said I've always nagged her to be independent, so she didn't have a choice.

> **"ATTITUDE IS EVERYTHING. REGARDLESS OF WHAT HAPPENS, A POSITIVE OUTLOOK ALWAYS SAVES THE DAY. IT'S HEALTHY TO GRIEVE ANY LOSS, INCLUDING VISION, BUT TO GRIEVE ALL YOUR LIFE IS AS BAD AS DEATH ITSELF. "**

EP Magazine: What is the role of the smart phone in helping blind individuals navigate the world outside the home? What specific apps are useful to you?

CLM: The smart phone allows most everything to be accessible. It can save the person who's blind and visually impaired to have everything at their fingertips – Uber, Door dash, Yelp, Kayak, Amazon, bank & restaurant apps, AirBnB, Delta app (because to me, Delta is the most blind-friendly).

EP Magazine: Despite being blind, aside from earning a living, you are a homemaker; you cook, do the laundry, walk your dog. It seems that nothing gets in your way to lead an independent life. Can you share your philosophy with other individuals who are blind?

CLM: It's all about making choices. I chose to get married and have a family. Thus, I determined to do what a wife, mother, and homemaker needs to do, except drive of course. Let me share the choice of the same co-worker who is blind. He chose to be single so he doesn't have to be burdened with serving a family. As a matter of fact, he didn't want any promotion because he didn't want the extra burden of relearning a different role, despite the pay raise. Whenever I discuss with him the issues I've been having, he always retorts, "That's exactly why I chose to remain where I'm at." Once you choose a role or position, as they say, you gotta do what you gotta do. If you can't do things despite trainings, or due to system limitations, you also need to accept that as weaknesses. Accept that having some weaknesses doesn't mean failure. It just means you need to focus on things you can do, and then excel in them. •

BLIND FAITH: Steve Mahan, who is legally blind, was the first non-Google employee to ride alone in the company's gumdrop-shaped autonomous car.

GETTING THERE

WILL THE ERA OF DRIVERLESS CARS MOBILIZE THOSE WITH DISABILITIES?

BY EP STAFF

For people with disabilities, mobility and transportation issues are one of the most difficult barriers they face in their struggle for accessibility and inclusion. Without a reliable system of friends and family, or the ability to pay for Lyft, Uber or conventional taxis, people with special needs are reduced to relying on public transportation, which is often not accessible, dependable or convenient.

Stuck In Neutral

Over 25 million people in the U.S. have disabilities that make traveling outside the home difficult, and they make fewer trips on average than those without disabilities, regardless of age, according to the U.S. Department of Transportation's 2017 National Household Travel Survey (https://nhts.ornl.gov). Seven out of 10 people surveyed in the NHTS said they reduce day-to-day travel because of their disabilities, and one-third of people who made zero trips said they stayed home because they're severely disabled or housebound.

Predictably, people with disabilities are more likely to encounter obstacles with nearly every mode of transportation. In a 2003 survey conducted by the U.S. Department of Transportation (www.ncbi.nlm.nih.gov/books/NBK11420), nearly 20% reported that their disability makes transportation difficult to use, with limited public transportation being the most frequent complaint.

However, progress in the field of autonomous, or self-driving cars over the last decade or so is a promising development for those with mobility, vision, and hearing impairments, including seniors and those with chronic health conditions. If autonomous cars are

PHOTO BY ERIC RISBERG/ASSOCIATED PRESS

developed with inclusivity as a primary goal, experts say the societal benefits could be enormous. For a segment of society that has been severely limited in its ability to move around, the prospect of easier access and increased independence that could one day become reality is an exciting one.

A 2017 Ruderman Foundation study found that mitigating transportation obstacles would enable employment opportunities for two-million people with disabilities.[1] And since approximately 4.3 million people with a disability face significant transportation barriers when attempting to travel to their medical appointments, autonomous automobiles could potentially save $19 billion annually from missed medical appointments.

Another potential impact of inclusive transportation is an increase in civic participation. A 2013 study by the Research Alliance for Accessible Voting argues that 3 million more people would have voted in the 2012 U.S. elections if those with disabilities voted at the same rate as those without.[2]

Technology Drivers

Perhaps the highest profile autonomous driving technology project in the U.S. today is Google's Self-Driving Car Project, started in 2009 and now named Waymo. Waymo, whose name was derived from its mission, "a new way forward in mobility," is a technology company working to make it safe and easy for people and things to get where they're going. Waymo is focused on improving everyone's access to mobility, while saving thousands of lives now lost to traffic crashes.

In October 2015, Waymo achieved the world's first fully self-driving trip on public roads in Austin, TX., in a car without a steering wheel or pedals. Waymo refines their technology through one billion miles of simulation testing each year, and the cars have self-driven over two-million miles on public roads across four U.S. cities.[3]

Steve Mahan, 63, of San Francisco, has worked extensively with Google since the project's early days. The executive director of the Santa Clara Valley Blind Center was the car's first passenger when the company tested its first autonomous ride in 2015. Over the course of its research and development, Waymo's vehicles have carried a number of disabled passengers.

Mahan had been gradually losing his vision over the last decade. He recalled experiencing the transition from using vehicles with driver-assistance systems to fully autonomous driving. "I had been in the Priuses and the Lexus vehicles that were adapted for autonomous driving, and they had normal control features. This was just to me the next logical step: to remove the human from the equation altogether," Mahan said.

Mahan hints at a new world of possibilities that are the aim of this research. "I miss driving," he said. "My experience with Google has been terrific, and I want it to happen. Everyone in the blind community wants it to happen. There are few things more American than getting in your car."

Waymo is engaged with several collaborators, including the Foundation for Senior Living in Phoenix and the Foundation for Blind Children, with the goal of ensuring its vehicles will be more fully accessible.

San Francisco-based zero emission self-driving company Cruise has similarly partnered with the National Federation of the Blind, the American Council of the Blind, Lighthouse for the Blind, and local communities to conduct usability studies and solicit information to guide its efforts.

Picking Up Speed

The American public is gradually becoming more familiar with self-driving cars. Some motorists drive newer cars that utilize some facets of the technology developed for the autonomous vehicles in research projects, such as lane-change warnings, automated breaking and parking assistance. Google's early test vehicles and their

GAINING MOMENTUM : THE FUTURE IS ON THE WAY WITH DRIVERLESS INNOVATIONS AND PUBLIC ADOPTION

Most prognosticators agree that it will be decades before autonomous vehicles are the dominant form of transportation, but pilot programs and commercial applications are rolling out faster than expected.

WAYMO ONE

Waymo has recently begun charging people for rides in the Waymo One, its fully autonomous driving system, in Phoenix, Arizona. Collaborating with Chrysler, Waymo has purchased thousands of Chrysler Pacifica Hybrid minivans for its services, and is said to open a new business model for companies developing or working on robo-taxi technology.

VOLKSWAGEN SEDRIC

SEDRIC is the prototype of an autonomous vehicle from the Volkswagen Group. SEDRIC comes to its passenger when summoned with the push of a button, navigates traffic, and makes all its own decisions. The concept car is suitable for car sharing and for personal use. SEDRIC can even perform errands, such as driving kids to school and then taking their parents to work, followed by collecting visitors from the station, picking up some shopping, and choosing a parking space – all at the push of a button, by voice command, or using the Volkswagen OneButton mobility app.

RENAULT EZ-GO

The autonomous EZ-GO concept car from Renault accommodates six people and is essentially a driverless carpooling vehicle. It can be summoned via either a mobile app or a roadside station, and it comes along to sweep you off your feet and into a spacious and airy interior. It can be booked by individuals or groups, and if Renault's vision comes to fruition, it will function like a new form of public transport for densely populated cities.

IMAGES COURTESY WAYMO; VW NEWSROOM; RENAULT UK

Waymo program cars are designed to replicate human response via a roof-mounted array of sensors that detect the car's location, surroundings, stationary and moving obstacles such as pedestrians, bicycles, and other vehicles. The cars navigate and observe traffic rules through sophisticated algorithms and controllers that preclude the need for driver input through steering wheels or brakes.

Since Waymo's later-generation autonomous vehicles have been designed to run without driver intervention, it has become more and more viable for people who are physically unable to operate a regular car to use them. Google realized that "the potential of a self-driver to help those with disabilities could be realized only if the human operator were taken out of the equation."[4]

These innovations in mobility and transportation are not limited to the Google's Waymo. Companies including Audi, BMW, Mercedes and Ford, are all currently working to develop some version of a driverless vehicle. Even Uber has declared an interest in releasing a fleet of driverless vehicles in the future.

In 2018, Renault unveiled the EZ-GO, an electric driverless ride-share vehicle with an oversized entry port that lifts up to reveal an extendable ramp for wheelchair access. In 2019, Volkswagen introduced its Inclusive Mobility Initiative. Through IMI, the automaker collaborates with outside groups like the Disability Rights Education and Defense Fund, the National Federation for the Blind, and the National Association of the Deaf to ensure the company's vehicles cater to people with disabilities. IMI's recommendations have already informed the design of a concept autonomous van – the VW SEDRIC – with tall roofs and doors designed to accommodate wheelchairs.

These corporations are aware that, in addition to the benefitting the disabled population, there are environmental and safety benefits to these systems. Automated vehicles are predicted to reduce the cost of traveling due to decreased insurance cost and cost of time due to improvements in productivity and driving comfort. These benefits could result in increased travel potentially increasing energy consumption by 4% to 60%.[5]

"Advocacy groups representing people with disabilities have a strong case regarding autonomous vehicles, in that what is good for their constituents is good for everyone. Nobody questions the need for elevators and curb cuts anymore, and no one will look back if we have vehicles that better serve all of our needs," says Sheryl Gross-Glaser, (former) director of the nonprofit Community Transportation Association of America.[6] "But just as we need to enable someone with a walker or wheelchair to enter and exit a vehicle, we need redundant technologies that serve people with auditory or visual impairments and technologies and designs that assist people with cognitive disabilities. Those exist, and they should be used in designing autonomous vehicles so that all autonomous vehicles will be accessible."

Going Further

Megan Strickfaden, a design anthropologist at the University of Alberta, is coauthor of a 2019 study that outlines problems for members of disabled populations, including those with low vision and hearing and with mobility challenges.[7] In the report, Strickfaden argues that even a vehicle with wheelchair accessibility features could fall short of acceptable usability and safety baselines. Steep road inclines could destabilize wheelchair ramps, and bumps in the road might cause a wheelchair to tip or fall. Improperly secured wheelchairs can result in injury and even fatalities. In the event of a crash, or other emergency, people with mobility or vision impairments may not be able to exit a vehicle.

In order to accommodate riders regardless of their physical abilities and skill levels, Strickfaden recommends a standard, "universally designed" driverless vehicle with a side entry ramp and user interfaces. "Universally designed" refers to the paradigm envisioned by Ron Mace at North Carolina State University's Center for Universal Design in which products are designed to be usable by all people without adaptation.

In addition, there is still much testing to be done. For instance, the vehicles have not mastered the navigation of unforeseen situations such as construction zones, extreme weather or malfunctioning traffic lights.

Strickfaden also advocates for additional assistive technologies for voice control, eye tracking and gesture recognition that could afford those with tactile, mobility, and hearing impairments more control without the need to make physical contact.

Roadblocks

Of course, the transportation industry will have to cope with meaningful impact from the adoption of this new technology. Insurance companies will have to modify their liability policies as automated vehicles increasingly reduce driver error as the cause of auto accidents. At the same time, the traditional automakers' model will change from individual ownership to usage-as-needed.

It's important to remember that as autonomous car technology becomes more available, private ownership is, in most instances, unlikely. Self-driving technology would add $5,000 to $20,000 to a vehicle's sticker price, so, for that reason, autonomous ride-hailing fleets like Waymo One appear to be the prevailing near-term model.

Cities and municipalities may be concerned about issues resulting from maintaining signage and markings according to vehicles' software standards and increasing the wireless-bandwidth capacity used by cars in traffic to communicate. Driverless cars would also cut into parking tickets and traffic citations, two other significant revenue streams for many cities.

Conclusion

Efforts to bring self-driving or driver-assisted cars to the public have the potential to greatly benefit those with limited ability. "We believe that one day there will be fully-automated cars that drive themselves under all circumstances," said Dan Flores, a G.M. spokesman, about the potential of driverless vehicles for those with disabilities.[8] "A lot of societal benefits are possible, but we're years away from achieving those benefits. •

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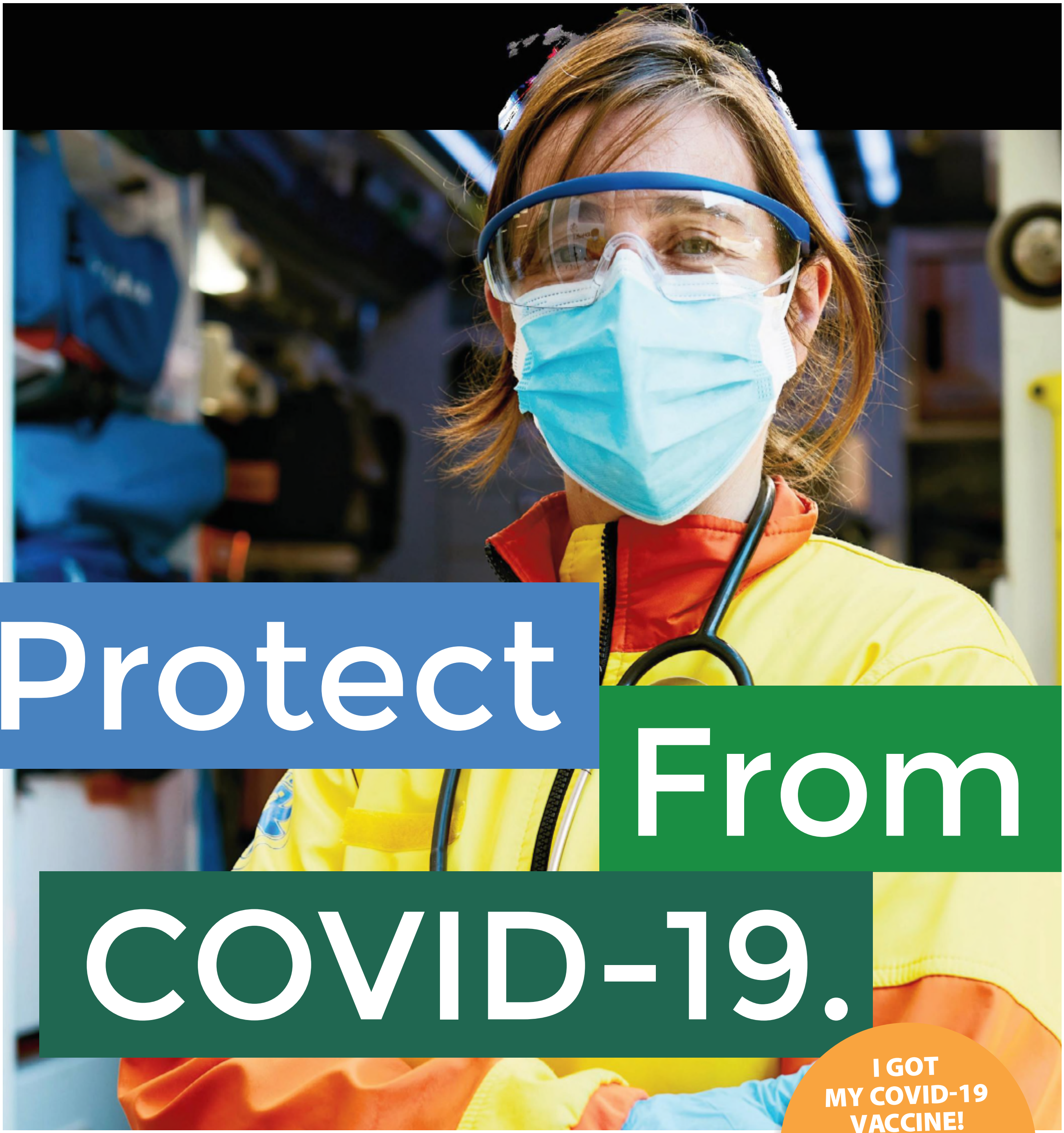

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Mobility

EP LOOKS BACK: MAY 2008

My Experience. My Perspective.

Transportation to Work Presents Problems

Career enthusiasts with disabilities have bigger issues getting to a job than finding a job.

By Markus Stegers

It is often natural in life for people to become suspicious or question why they were born in the first place. This usually happens as a result of a failed relationship, the loss of a job, or a traumatic accident. However, all these occurrences have something in common in that eventually those people will move on or be healed. Therefore. there is always hope in these situations. especially if they were able-bodied to begin with. But what if you are a person with a permanent disability? There may need to be additional effort made in order to make life meaningful. Time will not remove the many obstacles life has to offer. For instance, many children grow up believing that by the age of 15 or 16 they will go for their driver's test, pass, and use a vehicle as a means of transportation in their future occupation.

> The only thing left for me to ponder once I found a job was how to get *to* the job.

But what is not necessarily true for a person with a disability. Take my life, for instance. I had a brain injury when I was nine years old, resulting in a month-long coma and a year and a half of rehabilitation. I came our with a permanent physical and learning disability. Fortunately, it did not turn out to be so bad as I went back to sixth grade after a long hiatus. I was thankful because I was able to use a bus that had a wheelchair lift. So, for that time period, hope was restored.

After years of taking an accessible bus to school and back, I decided ro go to college and live on campus. Fortunately. my insurance paid for a motorized wheelchair, and the campus I lived on was fairly small so I had a great time going to class. Life was pretty easy at the time, but to my surprise. things started to unravel from then on.

Graduation signaled its own set of problems. Work was my number one priority. I was 22 years old at the time, and my future was going to be filled with a whole lot of work. The biggest problem was not the lack of jobs for a recent graduate who had very little experience, because I knew that something would eventually open up. But what seemed to be the biggest issue was transportation. I lived in Monmouth County in New Jersey, and I was a young adult so I had a big need for independence.

At the beginning of my post-college and pre-job life, it took me about a month and a half to find a job. The only thing left for me to ponder once I found a job was how to get *to* the job. I knew my parents would be willing to drive me, but I knew they had jobs also. It would be extremely difficult to coordinate their jobs with my job. There were bound to be some awkward waiting periods as we coordinated this successfully. Also, the last thing I would want is to rely on my parents to get to work, which would run contrary to my need for independence. Unfortunately for a time. hitching a ride with Mom or Dad was the scenario that worked best as we looked into the options that my home state of New Jersey had to offer.

My search into transportation options began with the Web site www.njfindaride.org, which was funded by Medicare and Medicaid for the purpose of providing accessible transportation options for people with disabilities. The New Jersey Department of Human Services is responsible for this Web site. After browsing this site to learn about the various transportation options that New Jersey offers. I found the attractive service called Access Link. which is meant for people who cannot use the traditional buses to get to their destinations. However, there are limitations on who Access Link can pick up, and even if there is a way of navigating around those constraints, you must be willing to accept the limitations of the routes they offer.

The Web site states that: "Access Link serves origins and destinations located within a 3/4 mile buffer of existing bus routes (NJDHS)." This is an outrage for those who live close to a bus stop but not close enough for Access Link to pick them up However, there are ways people can get around this. Unlike me, if you live on a street without heavy traffic and with sidewalks, you can maneuver yourself to this buffer zone. But this trek could be dangerous. It is just a shame to be eligible for this service but not really able to use it because of lack of confidence in being able to access it safely.

After Access Link, I looked for more specific modes of transportation that the County of Monmouth had to offer. I did find a type of service named BETS (Brokered Employment Transportation Services) on the Monmouth County Division of Transportation Web site. The Web site said: “This service provides transportation feeder service to existing public transportation systems, or in cases where these systems are non-existent, a ride within a reasonable distance from home to the worksite. Service is available between 6:00 AM-12:00 AM, Monday through Saturday.”

My eyes lit up, and without hesitation, I dialed the number that is listed on their Web site. My excitement was short lived when I found that there are limitations. First, you must be within 10 miles of your workplace. However, exceptions can be made if you are located only a few miles over the limit. Fortunately for me, I work only 13 miles from home, and they did accept that distance over their limit. However, for some people, a 10-mile distance limit could be difficult since today’s job market often requires a lengthy commute. Second, there is a waiting list before this service is available. For me, it was a year and a half wait, and there’s always the possibility of a change in job location or status during that time frame. For instance. some recent interviews I’ve had are for jobs over 20 miles away. Third, the fact that this service only runs six days a week can be an issue. While it does not affect me, people do work on Sundays sometimes.

So if a person does not have reliable transportation in getting to and from work, what will happen? Often, they will lose their job. So transportation challenges can often be one of the biggest stumbling blocks to having a successful vocational experience.

Schools seem to have become very efficient in providing accessible transportation. But, as a person who has experienced the challenges of adult transportation firsthand, I must ask this question: What is the point of education if we cannot utilize it in the job market? Something must be done! •

Transportation challenges can often be one of the biggest stumbling blocks to having a successful vocational experience.

Markus Kurt Stegers, who sustained a brain injury in 1994, graduated from Rider University in 2007 with a degree in journalism. There, he earned the Amy Silvers Memorial Award, which praised his achievements in scholarship, leadership, service, growth, and development in relation to personal, physical, and mental resources. In his short journalistic career, Markus has written for *Rider News* and *Able News*.

RETURNING TO SCHOOL:
CHILDREN WITH SPECIAL NEEDS AND MENTAL HEALTH POST-COVID

BY LAUREN AGORATUS, M.A.

The pandemic has disrupted the lives of students, families, and educators. There must be behavioral supports for students returning to school. Find out how schools are going to respond to the behavioral challenges that are sure to arise. Planning now would allow schools to put positive supports in place rather than using punitive actions later.

ONE STATE'S SOLUTION

The NJ Department of Education has put out a Quick Reference Mental Health Guide (see Resources). It is noted, "Multi-tiered systems of support (MTSS) and Response to Intervention (RTI) models provide frameworks for districts to develop tiered levels of prevention, support and intervention that can include comprehensive school mental health and therapeutic supports in addition to academic supports. One benefit of these frameworks is the development of an array of interventions that vary by intensity based on students' needs.

- *Primary Prevention or Tier 1 strategies to support all students;*
- *Secondary Supports for small groups; and*
- *Tertiary, or Tier 3 Intensive, Interventions."*

This guide has linkages to planning a school based mental health system, screening/referral, and the tiered supports mentioned above. It addresses school climate, social-emotional learning, mental health of staff, and positive behavioral supports.

HEALTH/MENTAL HEALTH PROFESSIONALS' IDEAS

The American Academy of Pediatrics (AAP) statement on returning to school and planning notes that "School policies should be guided by supporting the overall health and well-being of all children, adolescents, their families, and their communities but should also look to create safe working environments for educators and school staff. This focus on overall health and well-being includes addressing the behavioral/mental health needs of students and staff."

Students with Disabilities: The AAP recognizes that "The impact of loss of instructional time and related services, including mental health services, as well as occupational, physical, and speech/language therapy during the period of school closures and remote learning is significant for students with disabilities. All students, but especially those with disabilities may have more difficulty with the social and emotional aspects of transitioning out of and back into the school setting." Regarding behavioral health and emotional support, the AAP recommends that educators need training on how to support children post-pandemic. School mental health professionals must provide clear messaging to allay fears. IEP teams, which include parents, can discuss possible compensatory services.

The AAP recommends, "Special considerations are warranted for students with pre-existing anxiety, depression, and other mental health conditions; children with a prior history of trauma or loss; children with autism spectrum disorder; and students in early education who may be particularly sensitive to disruptions in routine and caregivers. Students facing other challenges, such as poverty, food insecurity, and homelessness, and those subjected to ongoing racial inequities may benefit from additional support and assistance." Lastly, the AAP notes that as suicide is the 2nd leading cause of death among adolescents age 10 and up, schools should develop referral mechanisms if a student is in crisis.

Addressing Social-Emotional Learning and Mental Health Needs: The National Association of School Psychologists (NASP) has school reentry considerations. These include:

- *Developing strategies for students, parents, and staff*
- *Having a referral system for targeted support*
- *Conducting universal social/emotional screenings*
- *Promoting well-being and resilience*
- *Establishing periodic informal check-ins with school mental health professionals*
- *Identifying high-risk students (e.g., pre-existing mental health, experience of loss, etc.)*
- *Holding classroom meetings with school mental health to discuss impact as a group*
- *Embedding social-emotional learning into core academic subjects*

GUIDANCE FROM THE U.S. DEPARTMENT OF EDUCATION

The Department has released "ED COVID-19 Handbook Volume 1: Strategies for Safely Reopening Elementary and Secondary Schools". This includes basics like stakeholder engagement, physical distancing, and masks. By the time this article goes to print, the Department will release Volume 2 (*see* www.ed.gov/news/press-releases). This volume will provide specific strategies to reduce the disruption for students, families, and professionals. The needs of underserved populations, who were the hardest hit, will be addressed. This will include:

1. *"Meeting the social, emotional, mental health, and academic needs of students*
2. *Supporting educator and school staff well-being*
3. *Addressing lost instructional time for students.*
4. *Stabilizing a diverse and qualified educator workforce*
5. *Ensuring equitable access to broadband and the devices needed to participate in remote learning*
6. *Supporting the effective use of technology for in-person learning and periodic shifts to remote learning*
7. *Providing school nutrition, regardless of the educational setting*
8. *Providing all students with access to a safe and inclusive learning environment*
9. *Extending learning time*
10. *Addressing resource inequities to provide all students with the educational opportunities they need to succeed, including access to a well-rounded education (including advanced courses, music, and the arts), quality educators, and integrated student support services*
11. *Using data to inform students, parents, and educators of progress and areas requiring additional support."*

In summary, the Department will provide research-based strategies to address the impact of COVID-19 on students, educators, and staff, especially for historically underserved students and communities that have been hit hardest by the pandemic.

These approaches are consistent with the Centers for Disease Control and Prevention's Whole School, Whole Child, Whole Community coordinated school health program, which consists of 10 interrelated components: health education, physical education and physical activity, health services, nutrition environment and services, social and emotional climate, counseling/ psychological and social services, physical environment, employee wellness, community involvement, and family engagement. (*See* www.cdc.gov/healthyschools/wscc/index.htm).

Students and their families, as well as educators, have been negatively impacted by the pandemic. Social-emotional learning concepts and behavioral/mental health supports will be crucial in recovering academic progress. Positive behavioral supports, being proactive rather than reactive, will ensure success for all students.

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

EXTRA HELP : STUDENTS WITH DISABILITIES AND SOCIAL-EMOTIONAL LEARNING AND MENTAL HEALTH NEEDS

NJ DEPARTMENT OF EDUCATION

Quick Reference Mental Health Guide

www.nj.gov/education/specialed/MHWG%20Return%20to%20School%20Mental%20Health%20Resources.pdf

American Academy of Pediatrics

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COVID Guidance for Safe Schools

https://services.aap.org/en/pages/2019-novel-coronavirus-covid-19-infections/clinical-guidance/covid-19-planning-considerations-return-to-in-person-education-in-schools

NASP

NATIONAL ASSOCIATION OF School Psychologists

NATIONAL ASSOCIATION OF SCHOOL PSYCHOLOGISTS

COVID-19 Resource Center

www.nasponline.org/resources-and-publications/resources-and-podcasts/covid-19-resource-center

School Reentry Considerations

www.nasponline.org/x55418.xml

U.S. DEPARTMENT OF EDUCATION

COVID-19 Handbook Volume 1: Strategies for Safely Reopening Elementary and Secondary Schools

www2.ed.gov/documents/coronavirus/reopening.pdf

COVID-19 Handbook Volume 1: Press Release

www.ed.gov/news/press-releases/us-department-education-covid-19-handbook-volume-1-strategies-safely-reopening-elementary-and-secondary-schools

U.S. Department of Education Continues Aggressive Plan to Safely Reopen Schools: Press Release

www.ed.gov/news/press-releases/us-department-education-continues-aggressive-plan-safely-reopen-schools

CDC

CENTERS FOR DISEASE CONTROL AND PREVENTION

Whole School, Whole Community, Whole Child (WSCC)

www.cdc.gov/healthyschools/wscc/index.htm

PEDIATRICIANS + TECHNOLOGY WILL IMPROVE FAMILY-CENTERED AUTISM CARE

BY COLLEEN KRAFT, MD, MBA

I have been a pediatrician for 31 years and know that all families want their children to grow and thrive and develop into caring and responsible people. Parents are usually the first to recognize when their child has a developmental concern.

However, the current pathway to diagnosis and treatment is variable and depends on local resources and systems of care. Yet, we realize that it is early identification and early intervention for these developmental concerns that can result in significant improvements in a child's language, communication, socialization skills and cognitive and behavioral development.

We also know that it is possible to identify and diagnose some conditions at an early age. Parents of children who are diagnosed with autism reported their first concerns on average as early as age 14 months.[1] While research has demonstrated autism can be identified in children as young as 18 months,[2] the average age of diagnosis has remained at over 4 years old for decades. Children of color, girls, and those from rural areas or disadvantaged socioeconomic backgrounds are also often diagnosed even later, and sometimes missed altogether.

The healthcare community attitudes and organizational culture are shifting to empower pediatricians in the early identification of autism. In 2020, the American Academy of Pediatrics (AAP) published an updated clinical report[4] on autism spectrum disorder, *Identification, Evaluation, and Management of Children with Autism Spectrum Disorder,* which provides pediatricians with a framework for the identification and management of at-risk children based on the available evidence. The reality is that pediatrics can and should have an active role that extends beyond screening – that assesses risk of delays – and to the child's evaluation that leads to a diagnosis.

Pediatricians are a trusted partner with the child's family, and an active partnership in evaluating the child's concerns while connecting them to services facilitates the best results for the child. And the good news is that innovative technology can further support the partnership between pediatricians and families.

UNIQUE POSITION OF PRIMARY CARE PHYSICIANS AND PEDIATRICIANS

Pediatricians have frequent access to children at a young age and greater context of a child and their family through well child visits. Pediatricians are indeed child health specialists. They are in a unique position to identify behavioral and developmental delays. Many are already managing behavioral health conditions such as ADHD, anxiety, and depression. **The next step is to develop and support primary care physicians so that the pediatric medical home can serve as the center and locus of care for children living with autism and developmental disabilities.**

THE ADVENT OF TECHNOLOGY-BASED SOLUTIONS

Pediatricians need the tools, training, and connections to broader support services to make informed diagnoses and next-step-in-care decisions. New technology can facilitate these processes.

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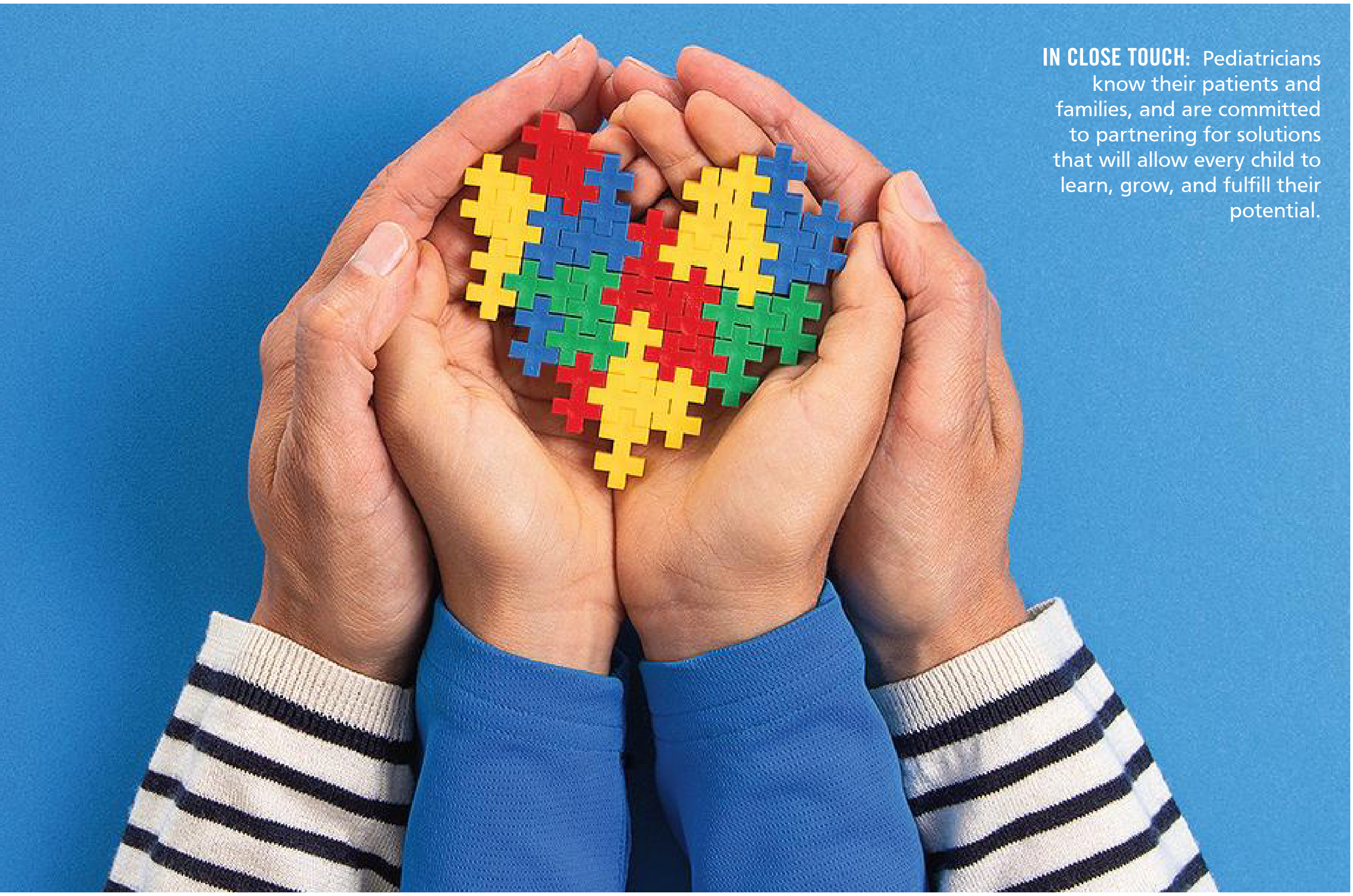

IN CLOSE TOUCH: Pediatricians know their patients and families, and are committed to partnering for solutions that will allow every child to learn, grow, and fulfill their potential.

An important development has been the incorporation of Artificial Intelligence and Machine Learning (AI/ML) into both diagnostic and therapeutics tools. AI/ML are computer and biostatistics programs that use information from sources, such as parent questionnaires and videos of a child to identify some of the most concerning features of developmental delay. A trained specialist can observe poor eye contact, repetitive movements, and abnormal patterns of speech; an AI/ML program can do so as well, often with greater speed and accuracy than a human observer. For pediatrics, these AI/ML tools can be incorporated into their practice, much like a lab test or X-ray. Clinicians and families can review the results together. The information that a trusted pediatrician already knows about the child, together with such tools, could lead to an earlier diagnosis of autism so that families receive the appropriate care they need sooner.

In contrast, a specialty evaluation often results in a much more detailed evaluation of a child's core deficits, with greater breadth and depth and insight into the child's concerns. But these evaluations, and subsequent diagnoses, often don't occur until 6-18 months after the child is referred. An earlier diagnosis means that families and clinicians can prioritize their child's concerns; start earlier evaluations in speech, behavior, and occupational therapy; follow the progress that the child is making; and brainstorm other concerns about the child such as sleeping or picky eating. Pediatric Specialists are very much needed when a diagnosis is challenging, or when a family needs more expertise in treating the child. **As the pediatric medical home becomes the locus of care for families with developmental concerns, many children could receive optimal and autism-specific therapies while their individual diagnostic journey is established.**

> *"AN EARLIER DIAGNOSIS MEANS THAT FAMILIES AND CLINICIANS CAN PRIORITIZE THEIR CHILD'S CONCERNS; START EARLIER EVALUATIONS IN SPEECH, BEHAVIOR, AND OCCUPATIONAL THERAPY; FOLLOW THE PROGRESS THAT THE CHILD IS MAKING; AND BRAINSTORM OTHER CONCERNS ABOUT THE CHILD SUCH AS SLEEPING OR PICKY EATING."*

Improving care for children is at the heart of every pediatrician. I predict technology will become a cornerstone of family-centered care, and we will make strides toward realizing the goals of high quality, individualized, equitable care. Pediatricians know their patients and families, and are committed to partnering for solutions that will allow every child to learn, grow, and fulfill their potential.•

ABOUT THE AUTHOR:

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WHEN WE "MISGENDER"

A TERRIFIED MAJORITY'S BEGINNER'S GUIDE TO MODERN PRONOUN USE

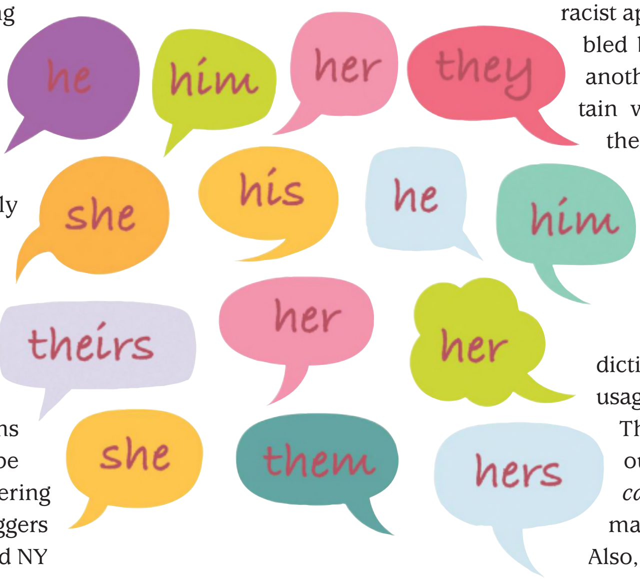
BY MICHAEL JOHN CARLEY (HE/HIM/HIS)

Mis-gen-der (verb): "to identify the gender of (a person, such as a transsexual or transgender person) incorrectly (as by using an incorrect label or pronoun)"

– Merriam-Webster[1]

Shelve my autism diagnosis for a moment. If you're a regular reader of my writings, think of me temporarily as a straight, primarily white, middle-aged male. Because when I lose the autism, I might, in another universe, belong to a demographic that is terrified by this increasing obligation to both understand, respect, and remember the pronouns of people who might not want to be referred to in the manner in which we would guess. And heck, now that I think about it? Forget the "primarily white" part – as likely equal percentages of people of color also have what we'll forgivingly call, "pronoun-use-resistance."

If you live in one of those parts of the world like Green Bay, Wisconsin – from which I just escaped – you may not have a lot of queer, cross-dressing or trans people in your daily lives, or even just people who don't want to be referred to in previously-predictable ways. You might live in a rural, or conservative part of the world where at work, at school, or as neighbors, you don't enjoy people either embracing another gender, rejecting gender itself, or who regard gender as nothing more than a social construct. As in all things undiversified, this hurts you more than you think; for while it simplifies your life, the isolation not only isolates you, you're often not privy to some incredibly beautiful as well as painful lessons about the human experience.



I get the fear!… You see on the internet lots of hip, young people trashing people like "us" because we referred to someone as "him" when they wanted to be called "her" or "them" – or even fancier pronouns like "ver" or "hir" – and you don't want to be called a bigot. AP has articles like "Misgendering is Not a Lightweight Mistake."[3] Young bloggers define it as "violence."[4] And in California and NY State, intentional misgendering is being incorporated as a legally-defined form of prosecutable harassment. Every time in an email signature you see someone using pronouns below their name or job title, you get annoyed, and think, "*What's this world coming to???*"

It's not completely new… From a grammatical standpoint, the first recorded use of non-standard pronoun use in the English language came from William H. Marshall, who in 1789 coined the word "ou" to replace either "he," "she," or even "it."[2] While not necessarily intended to be linked with sexual or gender identity, this factoid points to more questions than answers; as in other languages, like French, words are assigned genders. En Francais, the word "the" before a noun has more than variant, such as "La," "Le," or "Les," (the latter, for plural). English seems the standard for gender-neutral linguistics.

And from an identity standpoint, we used to list two genders, male and female. Then came "intersex" and "transsexual/transgender" to make it four options for identity. When I wrote my *The Book of Happy, Positive and Confident Sex for Adults on the Autism Spectrum… and Beyond!*"[5] in 2016 (though it has only been recently published) I wrote about Facebook's allowing 51 options to describe your gender identity and expression. Well, now we're up to at least 64.[6]

That's the intimidating part. The real and reassuring truth is that we're not all great brains. And even if we are great brains, no one's forcing any of us to understand or even align ourselves with the politics (though it would be great if we would). We're just asked being asked a bare minimum… to refer to someone in the manner in which they wish to be referred to. You don't *have* to understand it.

And you certainly shouldn't debate someone about it. The insult to Washington, DC,'s pro football team didn't just center on racist appropriation. The hurt was doubled because one group was asking another not to be referred to in a certain way, and the team was telling them that they were wrong to feel hurt. In the autism world, we felt that way about the word "cure." Growing up, I remember white kids actually defending their use of the N-word by citing that the word was in the dictionary, and that therefore their usage of the word was acceptable. The ideological colonialism if not outright implication that *"I don't care if you're offended"* just makes the bigotry hurt even more. Also, when marginalized people are defining themselves, the process often doesn't have a finish line. In the autism world, aside from objections to those words like "cure," and "disease," we actually don't agree on much… and that's ok. Over the decades, people of African descent have *often* changed the words used to describe them. The LGBTQ community has changed that acronym more than once. And this isn't a sign of internal confusion, or of marginalized people who *"can't get their &%$* together to decide on a term."* It's actually a sign of growth. When any marginalized community is convinced that they are finally allowed to talk freely about who they are (as the very act of marginalization stifles expression), they need time to talk amongst themselves before coming to you with a consensus-driven word that they all agree on. There's catch-up work to be done. They need to debate, disagree, resolve…and then maybe change again once they either learn more about themselves, or about themselves in context with the world's changing attitudes towards them.

When I ended 28 years of New York City living in 2014 for that Green Bay duration, I had maybe 12 colleagues and friends whose pronouns needed remembering. Having no such acquaintances in the Midwest, my discipline for this particular mindfulness went in the trash. Last summer, we moved back east and not only did I need to get that discipline back, but I also had a LOT more than 12 folks whose unique pronounce required memorization (global unique pronoun use having exploded during the six years we were taking care of in-laws). I also work part-time in a Diversity and Inclusion department at NYU, and therein have a huge responsibility to not send signals to people I care about that *"I don't care how they want to be referred to, I'm going to call them whatever I want because I think the whole thing is stupid."*

Of course the above is not what I'm thinking when I screw up and misgender. But part of what we all have to understand is that there are so many people who DO think that way, and whose fears have driven them to verbally assault, physically assault, and murder trans people in proportionally much larger numbers. Slavery, euthanasia… such unspeakable, and still not-explored-enough horrors can still leave pockets of existence today. But the open season of violence on transgender people is still rampant, and can be mainstream, i.e., not found in "pockets." Furthermore, a recent wave of anti-transgender legislature[7] pushes tells us that the discomfort to some, and hate for others, isn't going anywhere for some time.

> **"Back now in my spectrum persona, I can also tell you that a higher percentage of our spectrum folks, when compared to the neurotypical world, are LGBTQ. So this issue does affect the spectrum."**

So if I misgender – and I have (four times since coming home) – and someone really gets offended by it, I have to understand where they're coming from, and not feel unfairly attacked. As to the other three times I misgendered, the people in question know that I'm trying to get that discipline back after slacking in the Midwest, and they accepted my immediate and sincere apology with conviction and reassurance. I have to remember certain folks' pronouns about five times a week so I can safely report I feel the discipline getting better. But I still fear screwing up, and I wouldn't want that changed because it means that I care. It's a responsibility, and an obligation that I embrace, and not resent, because even as an outsider, I can see enough of the pain.

I believe that in the autism world, Autism Speaks still attracts fans who don't know of the organization's horrific past. So we who have autism have to disappointingly accept that our cause is not understood by everyone (yet!). But every once in a while, a spectrum person will cuss out an Autism Speaks fan who simply doesn't (yet!) know any better… and it sucks. If we misgender, and a trans person figuratively beats on us in a way that feels overdone… it sucks. But if we know the history, then we see that the difficulty to forgive is not coming from nowhere. This also happens in every space of diversity and inclusion. It's a process. If diversity was easy, folks like me wouldn't have jobs and we would have all figured this out a long time ago.

In even the most conservative circles can be heard the phrase "be kind." Well, that's really all you need to do. People not like you are asking you to refer to them a certain way. They don't need your opinion of their request. And to give it, isn't kind. It's the opposite.

And if you want extra credit, you can be an ally, or you can read about what's historically been done to trans and queer people; or cross dressers – like a wonderful ex-Board member of mine that I reported to when I was a UN rep, and whose recent passing I wrote about in a piece called "The Toughest Boss I'll Ever Have"[8]). Or you can read books like *She's Not There,* by Jennifer Finney Boylan…

And back now in my spectrum persona, I can also tell you that a higher percentage of our spectrum folks, when compared to the neurotypical world, are LGBTQ. So this issue does affect the spectrum.

I can't speak personally to what it must feel like to have what's called "gender dysphoria," which is when you are uncomfortable in your own body, or with your given name. But I believe that my neighbors aren't lying when they say that through day-to-day misery, the discomfort therein can drive them to extreme mental health challenges. Many who are undergoing the long and arduous surgical road to surgically transitioning, for instance, object to the idea that they are "changing" anything, because they never felt comfortable in their assumed gender to begin with. You can't betray a culture that never accepted you. So many of us look upon this procedure as an act of desperation, but it's the opposite. For many it's *the end* to feelings of desperation. And given the scrutiny it undergoes from a cruel outside word, must be defined as heroically brave.

I'm learning too. But it's like anything else: If you screw up (and misgender), just say you're sorry, and mean it.•

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Michael John Carley is the Founder of GRASP, a school consultant, and the author of *Asperger's From the Inside-Out* (Penguin/Perigee 2008), *Unemployed on the Autism Spectrum,* (Jessica Kingsley Publishers 2016), *The Book of Happy, Positive, and Confident Sex for Adults on the Autism Spectrum… and Beyond!,* (Neurodiversity Press 2021), and the column, "Autism Without Fear," which for four years ran with the Huffington Post. Currently he is the part-time Consultant for Disability Inclusive Culture at New York University, a writer for many, and on Mondays he sees individual clients. For more information on Michael John, or to subscribe to his free newsletter, you can go to www.michaeljohncarley.com.

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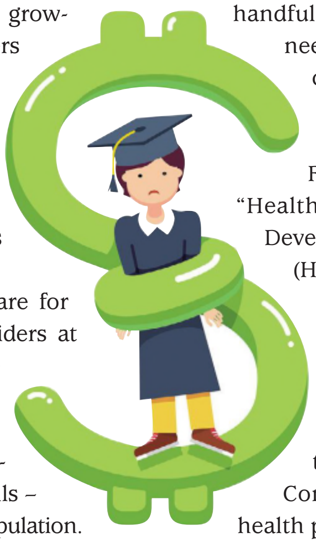
ADDRESSING HEALTH INEQUITIES THROUGH LOAN FORGIVENESS

BY STEPHEN SULKES, MD

Access to high quality, sensitive health care for people with Intellectual and Developmental Disabilities (IDD) remains a challenge nationwide.

Interest in serving this population continues to grow gratifyingly among medical students, including the growing numbers of members of the student chapters of the American Academy of Developmental Medicine and Dentistry (AADMD), encouraged by more and more medical schools incorporating disability-specific curriculum. However, there are multiple factors that work against these idealistic young professionals being able to continue to focus on this population.



Medicaid, the most common payor for health care for people with IDD, typically reimburses health providers at substantially lower levels than commercial insurance. Appropriate care for people with IDD takes extra time; office settings that are physically accessible and support communication and sensory challenges; and providers with special knowledge and skills – all of these are potential disincentives to serving this population.

Beyond this, young health providers often graduate from training with hundreds of thousands of dollars in educational loan debt. Serving a population that is high in needs, requires special skills and potentially extra years of training, no matter how rewarding, cannot compete with practice options that provide more family-friendly hours and levels of pay high enough to reduce their large loan burdens.

The issue in Developmental-Behavioral Pediatrics (the subspecialty of Pediatrics mainly focusing on children with IDD) is a big one now, but it is likely to get worse. Much of the workforce in this subspecialty is over age 50. Given the financial disincentives, young physicians are simply not signing up for the extra three years of training needed for Board certification. For the past several years, the number of available training slots has exceeded the number of applicants for fellowship training by one-third or more.

Fortunately, government officials in Washington, DC, and some states have begun to recognize this issue. For many years, health providers electing to work with Medically Underserved Populations, like low-income patients served in urban or rural health clinics, have been eligible for loan repayment or forgiveness. Recently, Congress authorized the Pediatric Subspecialty Loan Repayment Program, which will offer loan repayment for pediatric subspecialists who serve children in underserved areas. Advocacy is now underway to encourage Congress to allocate funds to this initiative. An analysis by the American Academy of Pediatrics in each state estimated driving distances for children to reach providers in 17 pediatric subspecialties. Nationwide, families needed to travel an average of 27 miles to see a Developmental-Behavioral Pediatrician. In many states, particularly those with widely distributed rural populations, distances were over 50 miles.

The barriers present in the pediatric range are compounded for those serving adults with IDD. Planning for an approved subspecialty of Developmental Medicine is underway, and there are a handful of programs training physicians in the special health needs of adults with IDD, but there is no formal certification process yet in place, and no promise of extra support for physicians who pursue such training.

A bipartisan group of legislators in the House of Representatives sponsored a bill in 2019 called the "Healthcare Extension and Accessibility for Developmentally disabled and Underserved Population" (HEADs UP) Act. This bill would have designated people with IDD nationwide as a Special Medically Underserved Population. If passed, this legislation would, among other benefits, support educational loan repayment or forgiveness for health providers primarily serving people with IDD. There is hope that the bill will be re-introduced in the current Congress, or that educational loan forgiveness for health providers serving people with IDD across the lifespan will be included in other upcoming legislation to support workforce development.

For people with IDD to achieve health equity, they need equal access to knowledgeable, caring providers. Until financial disincentives to serve this population are eliminated, the best training will have limited impact. Loan forgiveness is an easy and cost-effective way for the government to reduce these barriers, and with enough people speaking out in favor of it, Congress might be ready to open the door for it. •

ABOUT THE AUTHOR:

Stephen Sulkes, MD, Professor of Pediatrics at Golisano Children's Hospital in Rochester, NY, is former Director of the University of Rochester Leadership Education in Neurodevelopmental and Related Disabilities (UR LEND) Program, and Pediatric Discipline Coordinator, and Co-Director of the Strong Center for Developmental Disabilities (SCDD), Rochester's UCEDD. In the latter role, he is a member of the New York State Developmental Disabilities Planning Council. He is Board Certified in Developmental-Behavioral Pediatrics and Neuro-developmental Disabilities. He is a Fellow of the American Academy of Pediatrics (AAP), and of the Society for Developmental-Behavioral Pediatrics. He is a past President of the American Academy of Developmental Medicine and Dentistry (AADMD), and he has been Treasurer of AUCD, and a board member of the Society for Developmental Pediatrics. Among other honors, he was named Golisano Health Leadership Award winner for North America by Special Olympics International in 2017.

THE ROAD TO IDD COVID VACCINATION

MY OWN STORY

BY ALLEN WONG, DDS, EDD, DABSCD

I am a hospital-based dentist, Director of a Hospital Dentistry Program, Director of a Post-doctoral Advanced Education in General Dentistry, and a professor at the Pacific Dugoni School of Dentistry in San Francisco, California. My hospital is a major center for organ transplantations in the San Francisco area, and among my many responsibilities is to ensure that an organ recipient must be in good oral health prior to the surgery.

As patients are often emergency cases, that means I have to be available 24 hours a day, seven days a week, having to do surgical and restorative dentistry so the patients are infection-free, in good oral health, and able to receive the life-saving organ transplant they require. When the COVID-19 pandemic started in 2020, I was a frontline health care provider from March until August when I became infected and a patient myself.

It seems all too surreal, just a little over six months ago, due to COVID-19, I was in the intensive care unit for four weeks, fighting off being put on a ventilator almost three times. Never in my wildest imagination would I have thought that the act of breathing would ever be so difficult, draining, and painful. It started after a short visit to the emergency room days before for treatment of a herniated disk. After discharge within 48 hours, I spiked a fever of 105 and was re-admitted through the emergency room. This time, I was diagnosed with advanced respiratory disease. COVID-19. Upon utterance of the diagnosis, I watched my oxygen saturation drop along with my spirit as the medical team kept encouraging me to "take deep breaths."

The Academy of Developmental Medicine and Dentistry (AADMD) is an organization of physicians, dentists, and healthcare partners that advocates, educates, and increases access to care in an inclusive manner for those with intellectual/developmental disabilities (IDD). We at the AADMD realized early during pandemic crisis that this population was more vulnerable to contracting and dying from the disease, and also had been overlooked when it came to hospital visitor (care support) and ventilator considerations. We advocated with petitions for the above causes and created a white paper titled "COVID-19 Support Guidelines for Individuals with IDD During the Pandemic". It never occurred to me that one day, the research that our members, partners and I did to create the white paper, along with my own research, would one day lead me to become my own self-advocate.

On the first day of my COVID-19 admission, I realized how much physical and emotional strain it was, and thought to myself, "How could a person with IDD handle this?" I was isolated in a room, with no visitors allowed, had pressured oxygen constantly blowing into my nose, blood drawn on regular intervals a couple times a day, finger pricked for blood sugar levels, blood pressure taken, be given intravenous fluids, only ice chips (and no food for first three weeks to avoid aspiration), cathetered, and bed-panned. It all seemed never ending – not being able to sleep from the alarms, constant machine noises, and frequent interruptions for medical tests. The pain increased while my will decreased so quickly.

I was at a point where I made my peace with my God and was ready to be ventilated as the pain was so great. I vowed to myself that I would do whatever it would take to fight to get people with IDD protected as soon as the vaccine was available.

Finally, the medicines and my medical team at the hospital helped my body get better, though my emotional state was still very weak. After recovering and being discharged, I rehabilitated for a couple months, then trained to become a vaccinator. Thus began my journey to help get vaccinations to others.

Today, it is cause for celebration that our First Vaccination Clinic was held on March 27, 2021 at the Pacific Dugoni School of Dentistry in San Francisco. We were able to provide almost 300 vaccinations to those with IDD who reside and/or work in San Francisco residency. We partnered with the San Francisco Department of Public Health, Mayor's Office on Disabilities, Golden Gate Regional Center, Special Olympics (SO) Northern California,

ROAD TO A PROMISE: "I was at a point where I made my peace with my God and was ready to be ventilated as the pain was so great. I vowed to myself that I would do whatever it would take to fight to get people with IDD protected as soon as the vaccine was available."

ARC of SF, Henry Shein Cares, and several other agencies to get the word out. We had plenty of volunteers including behaviorist, NPs, translators, social workers, SO staff, GGRC staff, audiology support.

"I am proud of the University of the Pacific Dugoni School of Dentistry family, for educating practitioners and providing humanistic care for individuals with intellectual and developmental disabilities in our Special Care and hospital dentistry programs," said Nader A. Nadershahi, DDS, MBA, EdD (He/Him/His), who is Dean of the University of the Pacific, Arthur A. Dugoni School of Dentistry. "As we work to put an end to the COVID-19 pandemic, it has been incredibly rewarding to ensure equitable access and safely expand this care to provide life-saving vaccines. Thank you to our amazing leaders and volunteers."

A mandatory orientation was held for all volunteers about our population, disparity of care, importance for vaccination in our population, some basic need-to-know information (IDD, autism, CP, Down syndrome) regarding their condition, people-first language/etiquette, behavioral support, and making all of it a person-centered experience.

Some simple modifications of space, lighting (lowered), and sound were used to help provide a warmer setting. A couple rooms were set aside for those who could not mask, needed more private area, and/or needed stabilization. SO staff, behaviorists and others, helped entertain patients during the waiting period with stress balls, coloring sheets and health-related reading material (Passport). An hastily assembled orientation video for the patients (**https://sfdental.pacific.edu/media/VaccinationDayAtPacific.mp4**) was sent out in advance to show what was to be expected, in hopes of making patients more comfortable.

Though we requested J&J, we were given Moderna. Appointments were made for each person's second dose. Having a prepared Clinic with oriented volunteers for this population is more efficient and a better experience for the patient and caregiver. Let's encourage others to create more of these types of clinics.

Everyone scheduled was seen, and the volunteers all seemed to have a great experience. A great touchpoint for future health providers! My heart was full; we received smiles and nods of appreciation. Many commented that they had never worked on this population before and now have a great appreciation of the wonderful cooperation that existed. A parent wrote that her child, who had unsuccessfully attempted to get a drive-by vaccination, was successful today. She relayed their child's words which could not be said better: "Today, my future begins!"

My challenge is to encourage, whenever possible, more specific clinic sites for a population that is among the most vulnerable. I recently heard a terrific quote that went something like this: "Equality is being invited to the party; equity is being asked to dance." With what we accomplished, I felt as though we celebrated inclusive health by dancing… and the music was beautiful.

Through adversity, we grow stronger and more determined. I don't think I would have been able to get through my personal crisis had it not been for the love and support of my family and friends. They gave me hope when I was depleted.

As for me, I am feeling better… and this vaccination effort is my therapy.

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Allen Wong, DDS, EdD, DABSCD, is a professor at the University of the Pacific, Arthur A. Dugoni, School of Dentistry, San Francisco CA, and a Global Clinical Advisor with Special Olympics. He is President of the American Academy on Developmental Medicine and Dentistry (AADMD).

TALENT MAKES PLAYS. TEAMWORK MAKES A STATEMENT.

People with intellectual disabilities are excluded and discriminated against every day. It's time we team up and take to the field to change this. Together, as one, intolerance and injustice don't stand a chance.
Game On! Join the team at playunified.org

SPECIAL OLYMPICS
PLAY UNIFIED

FLORIDA SPECIAL OLYMPICS ATHLETES REFLECT ON THE PANDEMIC, CREATE NEW OPPORTUNITIES AND RETURN TO PLAY

BY AUSTIN PERT

The coronavirus pandemic has been with society for over one year. This year has been the most consequential in memory. Special Olympics Florida athletes are among the most resilient individuals on earth, overcoming a variety of disabilities to compete at high levels in sports.

Far more than just competition opportunities went missing during COVID-19, but as the pandemic reaches its apparent eleventh hour, a return to play plan sparks optimism and eagerness. Social interaction as well as the structure provided throughout school and work have been missing from many athletes' lives for the past 14 months. Some have overcome the situation better than others. Florida athlete Daniel Fundora, who was diagnosed with autism in his youth, but has implored peers to "escape the label," has focused on helping others with their personal goals during this time.

To understand the impact COVID-19 has had on many Special Olympics Florida athletes, one must understand the positive impact Special Olympics has had on many lives. Fundora, a 32-year-old with a Special Olympics Florida gold medal in softball, struggled with traditional team sport environments in his adolescence, as he did socially. But upon finding Special Olympics at age 23, he was able to leap into not just the art of sports, but also the science of goal setting, personal achievement and identity.

He lost 65 pounds and continues to work to keep the weight off. He recalls leaving his job at a supermarket warehouse to focus on running a boot camp for children and adults with developmental disabilities. Helping others with some of the same challenges he has faced throughout his life is something that fulfills him. Fundora's journey to personal success has been one he's been able to take control of, but the past year has taken control out of the lives of so many athletes like him.

The pandemic has cost millions of Americans opportunities that reach well beyond the realm of sports. Society has been asked to make painful sacrifices over the past year-plus. While they are a nuisance for anyone to have to follow, Special Olympics athletes have had to be extra flexible during this time.

Special Olympics Florida initiated a number of unique, digital outreach and at-home programs to help athletes get through the pandemic. They partnered with professional athletes in the "Fit 5 Like a Pro," program which featured well-known sports stars, including MLB's Dansby Swanson, the NFL's Cameron Brate, and professional tennis' Bob Bryan. These short, minute-long YouTube clips would encourage those in the Special Olympics community and beyond to practice healthy habits by "[exercising] five times per week, eat five fruits and vegetables daily, and drink five glasses of water a day," according to Special Olympics' YouTube playlist.

Special Olympics Florida started a "Fit and Well" Facebook group during the pandemic. It has 1,700 members. And they also launched a home fitness regimen on YouTube during the spring and summer months of 2020.

PLAY BALL: Softball's return to play will occur in phase two, which allows for indirect contact. Only in phase three are contact activities allowed.

PHOTOS COURTESY SPECIAL OLYMPICS/FLICKR.COM

Nobody knows this better than Hope Jacobson, who is Special Olympics Florida's biggest fan in Greater Miami. She has been involved with the organization since 1974. She has seen the nonprofit grow immensely over the years, from just 300 total athletes when she initially became involved to 8,000 athletes in Miami-Dade County alone. These athletes' ages range from early childhood to elderly – "you never age out of Special Olympics," Jacobson says.

The pandemic disrupted the natural flow of practices and competition in every sport. Depending on the locality of each Special Olympics program, the return to play phase may be varied.

BACK TO BUSINESS: In South Florida, bocce and equestrian have returned fully to in-person training, as have cheerleading, tennis, track and field, cycling and soccer. Where competitions are allowed to take place, activities may be staggered to reduce physical contact both on the field of play as well as the general site of competition.

For example, in phase one, no direct or indirect contact can be initiated. What this means is that contact sports would be off-limits, and non-contact sports with shared equipment would be too. Bocce ball is one of the signature activities allowed under phase one, as it is non-contact, any equipment can either be sanitized frequently or simply not shared, and the sport is outdoors.

Phase two allows for indirect contact, which is described on Special Olympics' website as "an activity where a ball or equipment is touched or in contact with an individual's hands/skin, and then directly touching another individual's hands/skin without disinfection." Only in phase three are contact activities allowed.

For example, according to Special Olympics, "Scrimmage, or full play of any sports such as basketball, football, volleyball, floor hockey, or soccer, etc. however, would be considered direct contact as bodies are regularly in contact with one another."

In South Florida for example, the following sports have returned fully to in-person training: Equestrian, cheerleading, bocce, tennis, athletics (track and field), cycling and soccer.

In regions where area competitions are allowed to take place, activities may be staggered to reduce physical contact, both on the field of play as well as the general site of competition. For example, an event involving 200 competitors and other individuals may be split up so only 50 people at a time are present. Another method of reduced-risk competition may be for each time to compete at separate sites, and for trading Special Olympics officials to collect scores from each individual team. In South Florida, a regional bocce tournament was held April 10, and the state tennis championships are scheduled for May 7 at Orlando's USTA campus.

A waiver must also be signed by each athlete, coach or volunteer before returning to practice or play.

The return to play process has been gradual. As far back as September 2020, "Coaches received extensive instruction on how to run practices consistent with COVID-19 safety protocols, and all participants were required to adhere to a COVID-19 Code of Conduct. For athletes who were not yet ready to return to in-person training, we continued to offer virtual options," said Special Olympics Florida official Linsey Smith in an email correspondence.

The return to play could not have come soon enough for many athletes. When athletes missed past events due to virus-related cancelations during the pandemic's height, it was a huge loss for so many deserving individuals. Fundora recalls the 2018 US Games in Seattle. He won a gold medal in stand-up paddle boarding and considers it to be his greatest achievement.

When athletics had to take a hiatus at the onset of COVID-19, it certainly turned many athletes' lives upside down. But beyond sports, the pandemic left unprecedented circumstances.

Athletes in Special Olympics Florida come from a variety of backgrounds, from lives with more means, to very humble situations. Many Americans have lost employment during the pandemic. Many Special Olympics athletes also dealt with COVID-19's adverse, non-pharmaceutical restrictions.

"Everything that the general population is suffering [from], the special [needs] population is suffering from," said Jacobson. Systemic inequalities facing the special needs community have forced it to bear the brunt of public health measures.

Different subsets of the Special Olympics population may handle the public health crisis inconsistently.

"Some of them respond better than others, especially amongst our population of people with autism spectrum disorders, one of the characteristics of the person on the spectrum, if they're truly autistic… they may be withdrawn and reticent and do not initiate social interactions, so it may not bother them as much," said Jacobson.

“Athletes like myself and anybody else [felt] lost,” says Fundora. “Everybody that has felt the joy of Special Olympics for so long and never want to leave or stop doing what they love, and suddenly, this pandemic took everything away from them. This pandemic has been punishing for everybody.”

Fundora’s personalized fitness programs for many Special Olympics Florida athletes were a focus for him in getting through this time. His classes are just one of roughly a dozen offered by athletes in Special Olympics Florida. It’s an “ongoing process” according to Fundora, but it’s been a great way for many athletes to stay in shape and stay occupied during the coronavirus shutdown.

Jacobson mentions how athletes continue to be disturbed by the disruption to routine and normalcy. She mentions a man in his 80s; he is her bowling coach. The man lives with his 76-year-old girlfriend whom he cannot marry so as to avoid complicating both of their social security benefits. He affectionately calls Jacobson his mom. Flattered, she tells him she can’t be his mom, but she can be his sister.

To go bowling, the man made an over half-hour commute to the alley his team practiced and participated at. Jacobson worries that the elderly gentleman will have lost some of his ability to drive by the time normality fully resettles. Public transportation and government-sponsored special transport services have picked back up as well, but health and safety still remain important considerations for athletes utilizing those options.

> ***“GETTING THROUGH THE PAST YEAR HAS BEEN SOMETHING MANY PEOPLE HAVE STRUGGLED TO ACCOMPLISH. BUT GOING INTO A DREARY 2020 AND ESCAPING INTO A SUNSHINE-FILLED 2021 TAKES LITTLE MORE THAN OPTIMISM AND A POSITIVE OUTLOOK.”***

Jacobson has met with a group of athletes over Zoom on Monday evenings to just touch base and provide some company. This group’s age range spans from school-age, to young adult, to middle age. She describes a young adult male who suffers from a loss of identity due to the pandemic’s consequences.

Many of her middle-aged and older athletes have elderly parents in assisted living or long-term care facilities. So, over the course of the pandemic and into its peak, they have not been able to see their mothers or fathers in these settings.

“He's frustrated, he's angry, he feels like he's lost; the pandemic has taken everything away from him. He is not able to do sports, he's not able to socialize, he doesn't have opportunities, he lost the job he had,” said Jacobson. She says that this individual is higher functioning and salvaged the recent months by creating his own new opportunity in personal training, working with other disabled men and women in fitness. For many athletes finding their way and rediscovering a purpose throughout the pandemic, physical fitness is a common denominator.

Special Olympics Florida has also played a part in helping its members and their families secure basic needs. The organization has athletes across socioeconomic backgrounds. If there is anything that has served as a staple of thankfulness and stability in an era defined by anything but, it is a hot family meal at the end of a long day. With many families facing insecurities even in good times, Special Olympics did not hesitate to answer the call from Miami-Dade County’s less fortunate.

Special Olympics Florida does not charge a dime to its members or families. They rely heavily on donations to fulfill its mission and give back to the community.

“During the summer, we had received a grant of money from UPS. Special Olympics asked the coaches to identify a bunch of parents that we would give gift cards to, so they could shop,” Jacobson said. The organization is still getting meals from some restaurants to deliver to needy households. Over 30 families in Greater South Florida received food assistance from the organization.

One family living deep in western Miami-Dade – a single mother and six children – lived without air conditioning. In addition to sponsoring delivered meals to this home, Special Olympics installed a window HVAC unit for the house.

While the situation seems grim at first glance, there is a light at the end of the tunnel with vaccines and safe, broad societal reopenings. Athletes are eager to get outside and into activities at all, no matter how different they may look and feel for now. Jacobson mentions an athlete by the name of Eddie who has been especially persistent to return to playing bocce ball.

“He wouldn't take no for an answer. It wasn't Eddie calling up and saying, Hey, Hope, can you do it [organize practice]? It was Eddie calling up and saying, Hope, we have bocce practice at 10 o'clock on Sunday morning, I need you to be there at 9 a.m. and bring all the bocce balls… you couldn’t say no to that.”

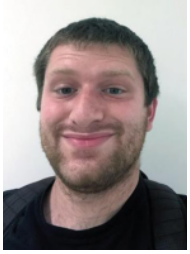
Jacobson also had to look out for herself during the pandemic. The days of packing 12 athletes into a van had to be at least temporarily put on the shelf. While better days may lie ahead, athletes without reliable transportation did feel the effects of fewer available carpooling options.

While there continue to be daily challenges to just living life successfully during this time, athletes like Fundora and Eddie are striving to just work on themselves. For all the adversity Fundora has faced throughout his childhood and adulthood, he ensures that others will get the same chance he has to improve themselves with physical fitness.

Getting through the past year has been something many people—with and without intellectual or physical disabilities—have struggled to accomplish. But going into a dreary 2020 and escaping into a sunshine-filled 2021 takes little more than optimism and a positive outlook.

Fundora is especially optimistic about the year ahead for athletics to return in a state better than ever. “They're going to prevail, they're going to fulfill, they're going to build confidence again,” Fundora said about the athletes in 2021. “Just like there were winners before, there will be winners again, when the time comes.” •

ABOUT THE AUTHOR:



Austin Pert is a senior at the University of Miami, studying journalism, public relations, and sport administration. His interest in the disability community stems from sports and wanting to promote an inclusive environment for all. He hopes to pursue a career in media or communications.

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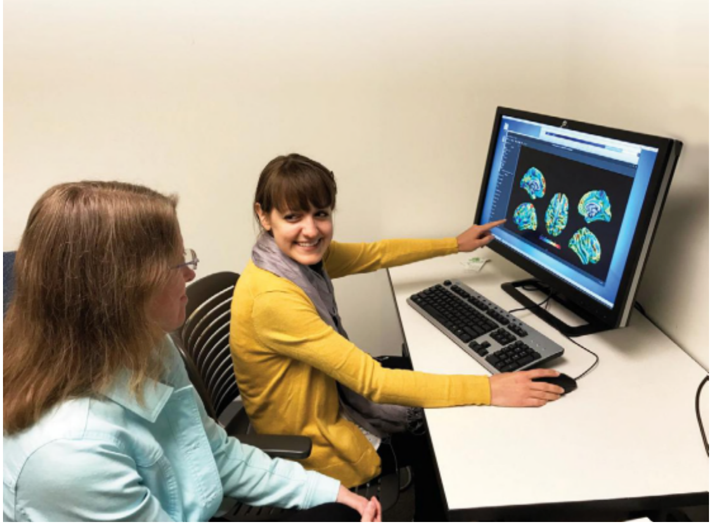

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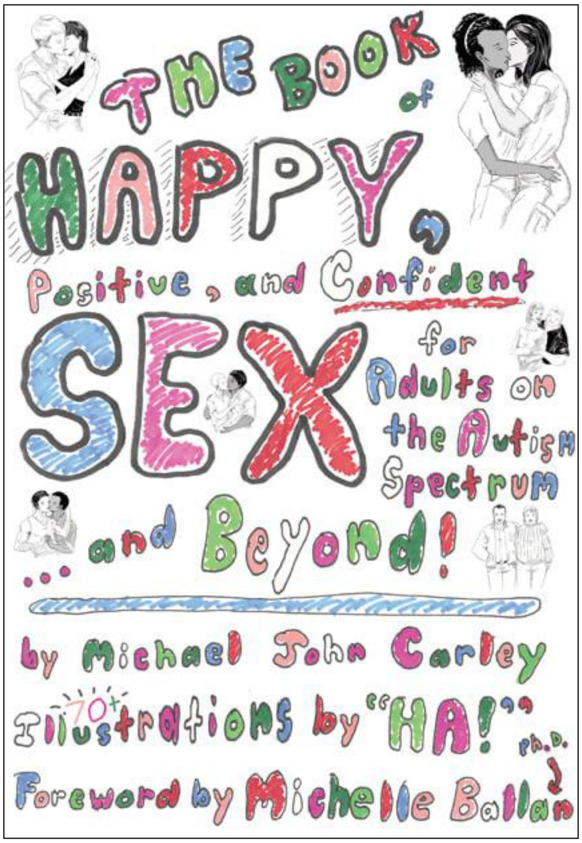
IES Brain Research Foundation thanks everyone who has participated & donated and wishes everyone a safe 2021.

"I'M NOT DOING THIS FOR SHOCK VALUE. IT'S IMPORTANT BECAUSE WE PEOPLE ON THE SPECTRUM ARE VERY LITERAL-MINDED. AND RELATIONSHIPS ARE VERY COMPLICATED. BUT SEX, WHICH CAN BE SO INTIMIDATING FOR OUR FOLKS, IS REALLY NOT THAT COMPLICATED, AND COMBINING THE TWO SUBJECTS OF RELATIONSHIPS AND SEX, AS WE SO OFTEN DO, IS JUST KIND OF MEAN."

A VERY NEW KIND OF SEX BOOK FOR PEOPLE WITH AUTISM "…AND BEYOND!"


THE BOOK of
HAPPY,
Positive, and Confident
SEX for Adults on the Autism Spectrum
...and Beyond!
by Michael John Carley
70+ Illustrations by "HA!" Ph.D.
Foreword by Michelle Ballan

AN EP MAGAZINE INTERVIEW

Exceptional Parent Magazine recently interviewed frequent EP columnist, Michael John Carley, on his third and newest book, The Book of Happy, Positive, and Confident Sex for Adults on the Autism Spectrum…and Beyond! *Michael John is currently the Consultant for Disability Inclusive Culture at New York University, the former founding Executive Director of both GRASP and ASTEP (now "Integrate") in New York City, a longtime K-12 school consultant, a former UN NGO Representative at the UN, and in 2000 he and his oldest son were both diagnosed on the spectrum within one week of each other.*

EP Magazine: Ok, before we get to the "sex," Michael John, why "...and Beyond!"?

Michael John Carley: I know that there are a lot more people out there for whom sex is a scary topic, and I didn't want them to think the book wasn't for them just because they didn't have an autism diagnosis. The book is appropriate for tons of non-apparent disabilities, for anyone who is neurodiverse, or just has a lot of anxiety around the subject. There are plenty of people who don't need a diagnosis to find sex really intimidating.

EP Magazine: We asked an associate of yours what was different about your book from prior special needs sex books, and she laughed and said *"Everything."* Is this true? And if so, how?

MJC: Well, maybe. I've written in more than one publication about how I strongly feel the autism world is surprisingly sex-negative, and so by contrast it certainly will appear that way. First off, it's a book that focuses on sex. Just. Sex. Not relationships. Sex. And I'm not

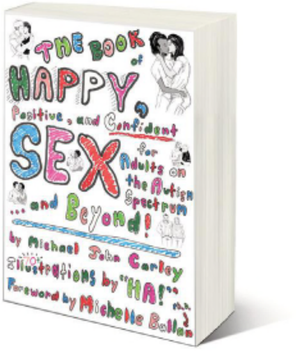
IMAGE COURTESY MICHAEL JOHN CARLEY/NEURODIVERSITY PRESS

doing this for shock value. It's important because we people on the spectrum are very literal-minded. And relationships are very complicated. But sex, which can be SO intimidating for our folks, is really not that complicated, and combining the two subjects of relationships and sex, as we so often do, is just kind of mean. The topic of sex involves this number of nerve endings in the frenulum, and this number of nerve endings in the clitoris, and this number in the anus...If all you needed to be confident was a book that focused primarily on physically pleasing another person, then why have we never before given them that book?

EP Magazine: But that almost makes it sound like a science book, and your book is not that, right?

MJC: *(Laughs)* True. I don't abandon cultural commentary, that's for sure. So where is it different? Let me give you some bullet points to print:

- For one thing, it's for people who already know the rules about how not to get an unwanted pregnancy, an STD, how not to go to jail as a stalker or yourself allow yourself to be abused. I do this because people need to understand that sex is about pleasure, and bonding. I'm lucky. Autistic people like me sometimes don't have great reciprocal love affairs, great careers, or great kids. But short of medical conditions, everyone of us can have sex. So sex might be the best thing we'll ever experience. And yet we teach it with constant fear disclaimers.... I'm trying not to shelve imperative lessons, but instead, with my book, I am asking that those conversations (and I say this in some preliminary notes in the book) be put into categories other than sex. STDs and pregnancies? Put them under health, not sex. Avoiding stalking charges should be filed under learning about the law, not sex. Sexual assault is about the law (if not violence), not sex. Otherwise, we say to the literal-minded spectrumite, "Sex is great! BUT..." Well, my book doesn't say "BUT..." I want people to hear the word "sex," and think, "Yay!"
- My Foreword writer, the brilliant sex genius, Dr. Michelle Ballan, calls it the most LGBTQ-friendly book of its kind." That means a lot to me.
- My book discusses porn and sex work quite differently, not only citing the inevitability that porn is our society's sex ed now. But so long as we provide the context to view porn with (especially how fake it can be), that porn can be quite healthy. Also, communities that take away access to porn and sex work have higher rates of sexual assault, and communities that make neither the purchasing or the selling of sex work illegal have the lowest rates of sexual assault.



Title: **The Book of Happy, Positive, and Confident Sex for Adults on the Autism Spectrum... and Beyond!**

Author: **Michael John Carley**

Publisher: **Neurodiversity Press**
Publication Date**: April 2021**
ISBN-13: **9781735696607**
Available at: www.neurodiversitypress.com

- My brilliant illustrator, "Ha!" has over 70 how-to drawings (not photos) throughout the book. But the people in his drawings aren't super-models. There are people of all ages, body types, colors, and orientations.
- Ok, so while it's not about relationships, there is a chapter on whether monogamy is right for you, and what are the alternatives (as polyamory comes in *many* variants...)
- Sexual orientation is not discussed through an "It's ok if you're gay" lens. Nobody should need yours or my permission as that, too, empowers the bigots. In general, our society's messy-headed attitudes towards sex stem from our attempts to culturally-control that which can never be controlled... except by biology and natural arousal.
- Asexuality is covered, whether you're a romantic within your asexuality or not.
- Masturbation, being so central in the lives of spectrumites, is discussed herein as an opportunity for self-love.
- BDSM is heralded herein as perhaps a *safer* sex life than "normal sex." I could go on. But one of the driving forces behind this book was that in order to spare caregivers some sometimes messy conversations, our community has censored our folks.

EP Magazine: So this IS a different book.

MJC: And yet, it's really not. I honestly don't have anything original to say in the whole book. This book is really just a translation of all that the neurotypical sex world has known about, written about, and printed, but that has never been filtered through into the world of non-apparent disabilities.

EP Magazine: How much of this book comes from first person experience?

MJC: By agreement with my wife, and outside of generalities, I have shared nothing other than an experience with erectile pills in the section on aging. I will state however, that if I did share my sexual experiences, readers might be disappointed. I'm fairly "vanilla" as they say. But I'm also a pluralist who knows that my ways of doing things do not work for everyone.

EP Magazine: Where can people get this book? I know you've made it hard to purchase.

MJC: *(Laughs)* Yes. My publisher, Neurodiversity Press, won't sell through Amazon. They're going to rob their authors of Amazon dollars, but I couldn't be more supportive of them. Neurodiversity Press will need people's word of mouth to survive. I'm Neurodiversity Press's first book, so we'll see if this works. The url to purchase is **www.neurodiversitypress.com/product-category/books** but people should explore the whole site at **www.neurodiversitypress.com**. It's a very cool company utilizing a very sensory-friendly website.

EP Magazine: Final thoughts?

MJC: Very few people are having "too much sex." The vast majority of us are not having enough. And nobody suffers from low self-esteem when they're having an orgasm.•

More info can be found on Michael John Carley's website at **www.michaeljohncarley.com/index.php/full-bio.html**.

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EP's Innovative New Digital Strategy

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

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

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

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

We're really proud of the new website and feel it will create the experience you're looking for when you pay us a visit. Check it out here: www.epmagazine.com

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THE $2,000 LIMIT

WHEN DOES MORE BECOME TOO MUCH?

BY ROB WRUBEL, CFP®

Several times a year, I get a call that sounds something like this: "What do I do? Help! SSI payments are building up in my son's account and it's getting close to $2,000. I keep spending and it just keeps coming."

Most of us don't complain from having too much money. It's why we play the lottery or look forward to a bonus or having a better-than-expected year in our investment accounts. More is always better, right?

We all know that more is not always better – last time I went to buy mayonnaise I was shocked by the options. Vegan. Real. Sugar-free. Smart-balanced. Canola. Keto. Seriously, do the companies sell enough of all of those? I don't need that many mayo choices and more is definitely not better in that category of the supermarket.

THE FINANCIAL FILE • A SPECIAL SECTION

Supplemental Security Income (SSI) is a federal benefit that pays a monthly income to people with a qualifying disability and limited resources. In 2021, the federal payment for an individual is $794. It's more for couples and some states add to the amount.

A person does not qualify if he or she has resources (assets) over $2,000.

Money in bank, investment and retirement accounts count towards the $2,000. Cars and real estate not used for personal use also count towards the limit. There are some exclusions. A person with a qualifying disability can own a house or condo to live in as a personal residence. "Use" items do not count – things like furniture, clothing, decorations and electronic devices.

SSI payments usually go to a checking account with the idea that the funds will be used each month on basic living – food, rent, clothing and medical needs. (Yes, I know, it's not enough for those needs, but that's the idea.)

There are issues to be aware of.

First, who is the owner of the account where the payments go? Is it your son or daughter or has a Representative Payee (rep payee) been appointed through the Social Security Administration? Mom or Dad can act as the rep payee.

If your family member receives the money in her own name, you will want to educate her about the $2,000 limit and help monitor the account to keep it below that. You don't have any authority to act directly and can only educate and assist as requested.

My daughter needs help with money. She does not know the difference between the value of $1, $10 or $100 when handed a bill. She does not, yet, know how to shop and spend money other than when I take her to buy the occasional purse, necklace or gift for a friend. Her account, when we get the approval for SSI, will have someone on it as rep payee.

The rep payee sets up the account and makes payments or transfers for spending on behalf of the person getting the funds – your son or daughter. This is what most families that I've been in touch with do. This puts someone with financial capacity in charge.

Even with that, money can pile up in the account if you're not careful. Many individuals with disabilities live at home or in care settings where most of their spending needs are met. They live at home and food, shelter, clothing, utilities and more are covered. As much as it seems like we never have enough money, in three months those $794 payments add up to more than $2,000.

There are strategies to put in place to make sure this doesn't happen. You can charge for rent, utilities, food and more to your family member. Keep good records and sweep the money you're charging every month from the rep payee account to your own checking account.

Another option is to sweep money each month from the rep payee account to an ABLE account. This preserves the funds for the beneficiary and is then accessible as needed to support your family member. Review ABLE rules and regs to stay compliant.

Consider a pooled-income trust. Some families use these vehicles as a way to preserve funds and to have a professional trustee involved that usually specializes in people with developmental disabilities.

Whatever choice you make, automate it as much as possible. Technically, your son or daughter could lose access to their monthly payments, health insurance and community programs if the account balance crests $2,000. Automating your sweep ensures that the funds move out of the account, no matter how busy or distracted you become.

More is always better, right? Well, not so much when important benefit programs are at risk.

Planning for the future is made up of lots of small steps that can lead to big results. Take a few minutes to automate distributions from the rep payee account of your family member. If you use the funds each month to support your household, it will show up like an additional paycheck. If you are fortunate enough, you can put it towards an account for future use.•

ABOUT THE AUTHOR:

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

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DEDUCTING IMPAIRMENT-RELATED WORK EXPENSES FROM YOUR INCOME (FORM 1040) AND FROM YOUR COUNTABLE INCOME FOR SSDI OR SSI

BY THOMAS M. BRINKER, JR.

Both the Internal Revenue Service (IRS) and the Social Security Administration (SSA) allow a taxpayer/recipient to reduce their income by allowable impairment-related work expenses (IRWE), but the application and reality of the deduction differ significantly.

On the income tax side, employees will rarely be able to utilize the deduction, especially with standard deduction amounts in excess of $12,000 for single individuals. However, the application under Social Security's rules can significantly impact the Supplemental Security Income (SSI) or Social Security Disability Income (SSDI) benefit received, since IRWE reduce income earned to determine "Countable Income" for SSI or "Substantial Gainful Activity" for SSDI.

THE FINANCIAL FILE • A SPECIAL SECTION •

The Income Tax Deduction for Impairment-Related Work Expenditures

As individuals with special needs mature and enter the workplace, many are entitled to claim itemized deductions for their unreimbursed impairment-related work expenses under Internal Revenue Code Section 67(d). Impairment-related work expenses refer to expenses that an individual with a disability incurs for attendant care services at the place of employment. The expense must assist the individual in maintaining employment and qualify as a trade or business expense. Qualifying individuals under this Section of the Internal Revenue Code are defined as those having a physical or intellectual disability (including but not limited to blindness or deafness) that is a functional limitation to employment or a physical or intellectual impairment (including but not limited to impaired sight or hearing) that substantially limits one or more major life activities, such as performing manual tasks, walking, speaking, breathing, learning, or working.

According to the IRS instructions in Publication 502, Medical and Dental Expenses, an employee should include impairment-related work expenses on his or her Form 2106, Employee Business Expenses, or Form 2106-EZ, Unreimbursed Employee Business Expenses. These expenditures are then transferred to Form 1040's Schedule A (Line 16), Itemized Deductions, as an unreimbursed business expense that is not subject to prior law's 2%-of-AGI limitation on miscellaneous itemized deductions (Publication 529, Miscellaneous Deductions). If you are self-employed, enter your impairment-related work expenses on the appropriate Form (Schedule C, E, or F) used to report your business income and expenses. Some examples of IRS approved deductions include:

- *An item(s) or service(s) that enables you to work (home computer, accessible vehicle);*
- *An item(s) or service(s) needed because of a physical or intellectual impairment (adaptive equipment, caretaker);*
- *A business expense paid that is unreimbursed by another source such as Medicare, Medicaid or private insurance (mileage to and from work);*

As with any business expense, the cost must be "reasonable" (i.e., the expenditure represents the standard charge for the item or service in your community, and is paid for in the month of employment).

IRWEs must be job related, but are not required to be solely incurred at your physical place of employment. If your employment requires having a laptop and specialized software at home for work, the unreimbursed cost of both are deductible on Schedule A for those itemizing deductions.

Example: Johnny is visually impaired and requires a reader to assist him while at work. The reader is available both during regular working hours and outside of Johnny's work schedule. Johnny can deduct the reader's fees for assisting him at work as an impairment-related work expense. (IRS Publication 529)

The Impact of Impairment-Related Work Expenses on SSDI and SSI

IRWEs, such as the cost of special transportation or work accommodations, can reduce your "countable income;" thereby increasing eligibility for SSDI or SSI disability benefits. For SSI, IRWE can reduce the impact of your income on your existing SSI benefits. **However, if you work at home, any expense incurred for work-related accommodations to your home can not be deducted as IRWEs if they are deducted as a business expense in arriving at net income for income tax purposes (i.e., Schedule A or Schedule C if self-employed).**

Substantial Gainful Activity for those Receiving Social Security Disability Income

The threshold amount for SSA purposes is an amount of earnings per month that will cause an individual to not be considered "disabled" under the program. The threshold amount is also referred to as the "substantial gainful activity" level of earnings. Certain expenses may be deducted from either employment or self-employment earnings for purposes of meeting the threshold amount. If SSA determines that your income exceeds the substantial gainful activity (SGA) threshold, SSDI or SSI disability benefits will be denied. **Note: If self-employed, IRWE include a deduction for un-incurred expenses which are not available for employees.**

These amounts are indexed annually for inflation. For 2021, the threshold amount is $1,310 per month. For the visually impaired, the threshold is $2,190 for 2021 per month.

The Supplemental Security Income Program

The Social Security Administration program for Supplemental Security Income (SSI) is a needs-based program and available only if individuals meet prescribed "countable income" and "countable asset" requirements. The Social Security Administration (SSA) administers this program. SSA pays monthly benefits to people with limited income and resources who are disabled, blind, or age 65 or older. Blind or disabled children, as well as adults, are entitled to SSI benefits. Unlike Social Security benefits, SSI benefits are not based on prior work or a family member's prior work.

OFF TO WORK : ELLIE'S CASE

An example from the SSA's website

Ellie receives SSI benefits due to her disability. However, she currently works part time, earning $1,025 a month, which is the only income she receives. She has the following work expenses (www.ssa.gov/ssi/spotlights/spot-work-expenses.htm):

$125 a month for union dues and insurance; and $250 a month to a special transportation service that she needs to get to and from work because of her disabling condition.

Although Ellie has work expenses of $375 a month, only the $250 of her earnings used to pay for the special transportation service are related to her impairment and not counted in determining the amount of her SSI benefit. *(Normally, public transportation is not an IRWE.)*

For Ellie, the $250 reduces her countable income in determining her SSI benefit as follows:

$1,025	**(Gross wages)**
-20	**(First $20 of income Not counted)**
-65	**(First $65 of earnings Not counted)**
-250	**(IRWE)**
$690	**divided by 1/2**
$345	**(Countable income)**
$794	**(SSI Federal benefit for 2021) less**
-345	**(Countable income)**
$449	**(SSI Federal benefit)**

Ellie is entitled to an earned income reduction in the amount of $335 ($1,025 of earnings less the first $20 of her earnings, plus the first $65 of her earned income and $250 of IRWE with the balance reduced by 1/2 of the amount of her earned income over $690). The difference between the FBR ($794) and her countable income ($345) is $449, which is her 2021 SSI benefit amount.

If Ellie had not incurred any IRWE, her countable income would have been $470 ($1,025 of earnings less the first $20 of her earnings, plus the first $65 of her earned income with the balance reduced by 1/2 of the amount of her earned income over $940). The difference between the FBR ($794) and her countable income ($470) is $324, *which is $125 less than had Ellie incurred the IRWE of $250.*

SSA does provide an Impairment-Related Work Expense Request Form that requires a formal request for consideration of Impairment-Related Work Expenses (IRWEs). The Form can be found at www.worksupport.com/documents/SubReqTemp.pdf.

However, if individuals receive too much income or own too much property ($2,000 for individuals and $3,000 for couples), eligibility is at jeopardy for the SSI program.

Social insurance programs (i.e., SSDI) are potentially available, regardless of income or assets, and typically depend on the amount contributed to the program, such as Social Security wage tax.

The Impact of Impairment-Related Work Expenses on "Countable Income"

As previously indicated, IRWEs, such as the cost of special transportation or work accommodations, can reduce "countable income;" thereby increasing eligibility for SSDI or SSI disability benefits or, for SSI, reducing the impact income may have on existing SSI benefits. In a recent *SSA Spotlight,* the Administration also cites out-of-pocket expenses for medical services such as doctor visits and some attendant care services incurred to prepare you for work, attending to you while you are at work, or transporting you to and from work. SSA may also allow certain out-of-pocket expenses for transportation and modifications to your home, car, or van to allow you to work. The expense must be un-reimbursed, related to your disability(ies), and needed in order for you to work.

Employees

SSA allows employees to deduct IRWEs when reporting their income; however, wage-earners *cannot* deduct un-incurred business expenses (applicable only for self-employed). If countable income exceeds the following amounts, the applicant/recipient will be ineligible for SSI:

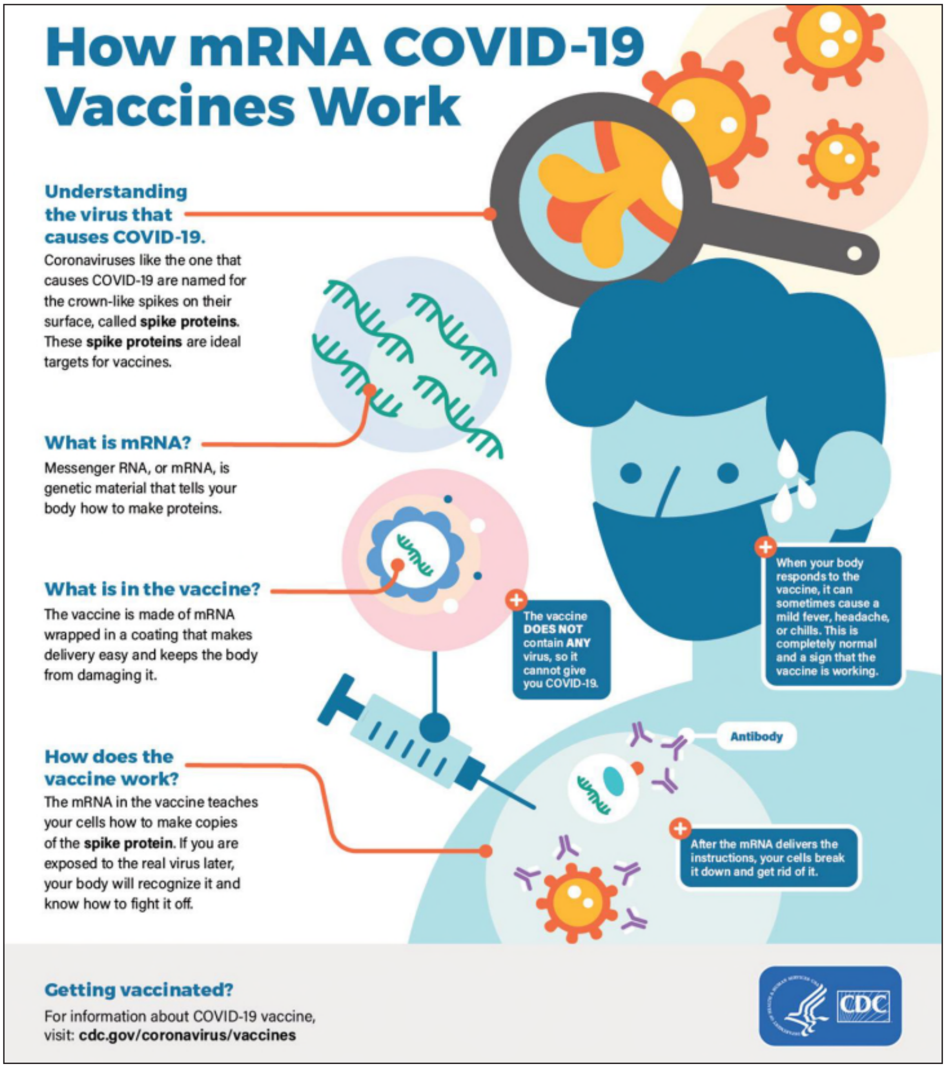
2021 SSI Monthly Income Limits

Individual whose income is only from wages: $1,673

Individual whose income is not from wages: $814

Couple whose income is only from wages: $2,467

Couple whose income is not from wages: $1,211



Understanding the virus that causes COVID-19.
Coronaviruses like the one that causes COVID-19 are named for the crown-like spikes on their surface, called **spike proteins**. These **spike proteins** are ideal targets for vaccines.

What is mRNA?
Messenger RNA, or mRNA, is genetic material that tells your body how to make proteins.

What is in the vaccine?
The vaccine is made of mRNA wrapped in a coating that makes delivery easy and keeps the body from damaging it.

How does the vaccine work?
The mRNA in the vaccine teaches your cells how to make copies of the **spike protein**. If you are exposed to the real virus later, your body will recognize it and know how to fight it off.

The vaccine **DOES NOT** contain **ANY** virus, so it cannot give you COVID-19.

When your body responds to the vaccine, it can sometimes cause a mild fever, headache, or chills. This is completely normal and a sign that the vaccine is working.

After the mRNA delivers the instructions, your cells break it down and get rid of it.

Getting vaccinated?
For information about COVID-19 vaccine, visit: **cdc.gov/coronavirus/vaccines**

According to "Understanding Supplemental Security Income" on the SSA's website, not all income counts for the SSI program. The most common adjustments are:

- *the first $20 of most income received in a month, and*
- *the first $65 of earnings and one-half of earnings over $65 received in a month, and*
- *the cost of impairment-related work expenses for items or services that a person with a disability needs in order to work.*

How Impairment Related Work Expenses Affect Current SSI Recipients

When applying for SSI, the SSA will determine whether you have substantial gainful activity (whether your income level qualifies you for the benefit). As indicated, IRWEs can be subtracted from your income in determining SGA and may indicate that an applicant qualifies for SSI. Once you are approved for SSI, the SSA no longer considers SGA when determining your eligibility for benefits. However, if you do work, your earnings can affect your monthly benefit amount. This is because your benefit is the difference between your "countable income" and the federal benefit rate (for 2021, the Federal Benefit Rate is $794). IRWE deductions reduce the impact of earnings in qualifying for SSI and can increase your benefit

Where to Seek Answers?

If you are already receiving benefits, contact the SSA for more information about whether you have any IRWEs. It may also be helpful to talk with an experienced disability or special needs planning attorney, a Chartered Special Needs Consultant (The American College of Financial Servicers), or a financial planner specializing in SSA benefits and planning for those with special needs to see how employment may impact eligibility for benefits.

20 CFR § 404.1576 - Impairment-related work expenses (Social Security).

26 U.S. Internal Revenue Code § 67 (Income Taxation) •

ABOUT THE AUTHOR:

Thomas M. Brinker, Jr. is Adjunct Professor & Chair, MM Center for Special Needs Planning, The American College of Financial Services; Professor of Accounting, Arcadia University.

FROM OUR FAMILIES... TO YOUR FAMILIES

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SPECIAL NEEDS CONSULTATIONS

The special needs consultants available through Military OneSource Exceptional Family Member Program Resources, Options and Consultations, or EFMP ROC, can answer your questions and concerns related to your child or adult family member with special needs.

MAKING A GAME PLAN: Your consultant can connect you with information, resources, services and more, including information about specialized doctors, medical-equipment resources and medical benefits, early intervention and special education, and more.

Consultants are professionals with master's degrees and extensive experience in the disability field. They're also trained in military programs. When you have your call, you can expect your consultant to:

- *Listen to what your family needs*
- *Complete a needs assessment*
- *Determine and evaluate what resources your family already has or has tried*
- *Guide your family toward the help you need*
- *Conduct three-way calls between you and TRICARE health care and arrange warm hand-offs to installation EFMP Family Support staff or other experts to assist you*
- *EFMP has enhanced support for families with special needs through ROC. EFMP ROC provides ready, one-source access to specialized resources, options and customized consultations for military families with special needs. Call or live chat at any time to schedule a specialty consultation by phone or video.*
- *EFMP connects you with consultants who have subject matter expertise in education, the military health care system, TRICARE coverage, state and federal programs and more.*

EFMP ROC provides extra support through three-way calls with health care and other experts. Go to EFMP ROC at **www.militaryonesource.mil/confidential-help/specialty-consultations/efmp-roc**

HOW CAN SPECIAL NEEDS CONSULTANTS HELP?

Your consultant can connect you with information, resources, services and more, including:

- *Information about specialized doctors, medical-equipment resources and medical benefits*
- *Early intervention and special education*
- *The Education Directory for Children With Special Needs,* (**https://efmpeducationdirectory.militaryonesource.mil**) *which helps military families make informed assignment decisions and easier transitions*
- *Options for when your child graduates from high school*
- *The Exceptional Family Member Program* (**www.militaryonesource.mil/family-relationships/special-needs/exceptional-family-member/the-exceptional-family-member-program-for-families-with-special-needs**)
- *Support for adults with special needs* (**www.militaryonesource.mil/family-relationships/special-needs/special-needs-benefits**)*, including information on insurance, Social Security Disability Insurance* (**www.militaryonesource.mil/family-relationships/special-needs/support-for-families/what-is-social-security-disability-insurance**)*, Supplemental Security Income* (**www.ssa.gov/benefits/ssi**)*, Medicare* (**www.medicare.gov**) *and Medicaid* (**medicaid.gov**)
- *Research on grants, support groups, in-home care and help during deployments*
- *Recreational referrals to specialized summer camps and other extracurricular activities*
- *Referrals to legal and financial resources* (**www.militaryonesource.mil/family-relationships/special-needs/special-needs-resources**) *for families with special needs, such as guidance on special needs estate planning and creating a special needs trust*
- *Caregiver wellness referrals for support groups, stress management, non-medical counseling* (**www.militaryonesource.mil/confidential-help/non-medical-counseling**) *and health and wellness coaching* (**www.militaryonesource.mil/confidential-help/specialty-consultations/health-wellness-coaching/health-wellness-coach-the-essentials**) *and other resources*
- *Respite care* (**www.tricare.mil/CoveredServices/IsItCovered/RespiteCare.aspx?sc_database=web**) *resources through TRICARE* (**www.tricare.mil**) *or community programs, and through each service branch*

Special needs consultants are ready to support you. Consultations are available via phone or video session. Make an appointment 24/7 with live chat or by calling 800-342-9647.

– Military OneSource

PCS: THE BASICS ABOUT PERMANENT CHANGE OF STATION

A permanent change of station is part of military life. Experiencing different parts of the country and the world is a unique benefit of military service.

In fact, travel and visiting new cultures may have been among the reasons you joined the military. More than 400,000 service members PCS annually, so you can expect PCS orders to be part of your military career.

WHAT YOUR PCS ORDERS INCLUDE

Unlike temporary duty assignments, permanent change of station orders are a longer-term assignment, generally two to four years. Broadly speaking, your orders will tell you where you'll be moving to – either CONUS or OCONUS.

- *CONUS: Moves inside the continental United States*
- *OCONUS: Moves outside the continental U.S. These are typically overseas moves, but also include Alaska, Hawaii and U.S. territories.*

Your orders will also include:

- *Issue date*
- *Issuer's name*
- *Order number*
- *Authorized locations*

If you are going to coordinate your move through the military, you will need to have this information handy.

ORGANIZING YOUR MOVE

Moving is rarely simple, and in times of global uncertainty it is more important than ever to know the best ways to organize the logistics of your move and act fast once you get your orders. The Department of Defense provides a variety of resources to help make your PCS as easy and safe as possible:

- *Military OneSource is available 24/7 anywhere in the world with expert moving consultants and online tools and resources to help you get organized and settled. Call anytime to speak with a consultant, or set up an online chat. Learn more about moving in the military* (**www.militaryonesource.mil/moving-housing/moving/pcs-and-military-moves**) *and find out how our experts can help you master your PCS.*
- *Move.mil, the official Department of Defense customer moving portal is moving to Military OneSource. In the next few months, you'll be able to access resources and tools available from U.S. Transportation Command here on Military OneSource. Some information is here now, including:*
    - Customer support for moving household goods: **http-www.militaryonesource.mil/moving-housing/moving/pcs-and-military-moves/#moving-experts**
    - Resources to help you plan your shipment: **www.militaryonesource.mil/moving-housing/moving/pcs-and-military-moves/#related-content**
    - Link to log in to the Defense Personal Property System to schedule your move: **https://dps.move.mil/cust/standard/user/home.xhtml**

Additional resources and information will be coming to Military OneSource soon. As we work toward giving you one source of access for all your moving needs, you can still use Move.mil for tools, tips and more.

- Plan My Move (**https://planmymove.militaryonesource.mil**) is an online tool that helps you create, organize and manage your PCS through customized checklists, so you can stay on top of important to-dos as you go through the moving process. Answer a couple of questions and you're on your way to building your custom checklist.

RELOCATION ASSISTANCE AND RESOURCES

There are a variety of resources both online and through your installation to help you transition before, during and after your move:

- *Your installation's Relocation Assistance Program* (**https://installations.militaryonesource.mil/?looking-for-a=program/program-service=9/focus=program**) *is a great source of information and support for moving and getting settled at your new duty station. Relocation experts offer pre-departure briefings, newcomer orientations, and information about job opportunities, child care, school liaisons and more. Find out how to put the military's relocation assistance program to work for you.*
- *The MilitaryINSTALLATIONS* (**https://installations.militaryonesource.mil**) *website provides comprehensive information about military installations worldwide. Search for programs and services, access information on temporary housing, check-in procedures, schools, surrounding community and more.*
- *The military sponsorship program* (**www.militaryonesource.mil/moving-housing/moving/sponsorship/sponsorship-the-essentials**) *helps service members and families as they transition to a new duty station and community. Typically, your unit will assign a service member of similar rank and family make-up to help you learn the ropes at your new duty station. Learn more about the benefits of sponsorship in the short Sponsorship and You course* (**www.militaryonesource.mil/moving-housing/moving/sponsorship/sponsorship-the-essentials**) *available on MilLife Learning.*
- *The Blog Brigade website* (**https://blogbrigade.militaryonesource.mil/blogs/moving/**) *offers insider moving tips and military life insights from other service members.*

Whether this is your first PCS or you're a seasoned professional, let Military OneSource help you master your move so you can get on with your mission.

– Military OneSource

TRICARE

COVID-19 VACCINATION

GET THE FACTS

GETTING THE COVID-19 VACCINE AT CIVILIAN PHARMACIES

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

NETWORK PHARMACIES

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

NON-NETWORK PHARMACIES

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

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

ACTIVE DUTY SERVICE MEMBERS:

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

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

As of Feb. 5, 2021

TRICARE®

BLUE STAR MUSEUMS

Museums across America are rolling out the red carpet for active-duty, National Guard and reserve service members and their families between Armed Forces Day and Labor Day. Simply flash your ID and enjoy free access through the Blue Star Museums initiative.

STATE OF THE ART: Typically, more than 2,000 museums across America participate in Blue Star Museums each summer. These include children's museums, art museums, history and science museums, zoos, and nature centers.

The program is a collaborative effort between the Department of Defense, the National Endowment for the Arts, Blue Star Families and participating museums. The Blue Star Museums initiative (ww.arts.gov/initiatives/blue-star-museums) provides even more ways for you and your family to explore your community, spend time together and share adventures.

BE IN THE KNOW

Here are some helpful things to know about the Blue Star Museums initiative:

- *You'll be in good company. More than 2 million military families have enjoyed Blue Star Museums since the program launched in 2010. Join their ranks, if you haven't already.*
- *Your ID card is your ticket to the museums. Just show your common access card, or DD Form 1173 or 1173-1 identification card.*
- *Your admission is free, so there's no need to limit yourself. Explore fine art, history, science, children's museums, arboretums, historical parks, nature centers and more. Find participating museums* (www.arts.gov/initiatives/blue-star-museums) *near you or along your travel route.*
- *Your Information, Tickets and Travel office* (www.militaryonesource.mil/recreation-travel-shopping/recreation/tickets-tours/information-tickets-and-travel-your-key-to-fun) *can add to your fun. As you map out your museum visits this summer, check with the office to find additional attractions in your area.*
- *You can enjoy a staycation* (www.militaryonesource.mil/recreation-travel-shopping/travel/travel-planning/avoid-travel-stress-and-save-money-with-a-staycation) *in your new community. If you're settling into a new duty station, take a break from unpacking and explore. Blue Star Museum visits will help you get to know the place and its people.*

Make it a blockbuster summer. See how many Blue Star Museums you can explore. Be sure to take advantage of the other great opportunities your morale, welfare and recreation program offers (https://installations.militaryonesource.mil/?looking-for-a=program/program-service=5/focus=program).

The 2021 Blue Star Museums program begins on Armed Forces Day, Saturday, May 15, 2021, and ends Labor Day, Monday, Sept. 6, 2021.

– Military OneSource

ABOUT BLUE STAR MUSEUMS

Blue Star Museums

Blue Star Museums is a collaboration among the National Endowment for the Arts, Blue Star Families, the Department of Defense, and museums across America offering free admission to the nation's active-duty military personnel and their families, including National Guard and Reserve. For more information on Blue Star Museums, please see the FAQ page of the National Endowment for the Arts at www.arts.gov/initiatives/blue-star-museums/frequently-asked-questions

Blue Light on the Corner

Last April 1st, my husband rigged a light to our porch and screwed a blue light in our lamp by the front door so the color blue would shine from our porch. I was prepared to be the only blue light in our neighborhood.

"We don't move on, we must move forward," according to Nora McInerny's TED talk over grief. Moving forward with autism can still be lonely and last month, I was reminded of just how lonely I can feel. As many of us know, each year, April is called "Autism Awareness Month," though what I usually say to others is that every month is autism month. Over the years, I've looked forward to April. Once in a while, there will be an inspirational story shared on the news, or I'll see that the local community where I'm living at the time has hosted an autism awareness walk.

Frankly, I've come to the conclusion that I've taken it for granted. Every year, the installation where we live will either put on a small autism walk, or an awareness booth to create conversation about autism, and have a place where families can get together and share experiences. There are years I'm more involved than others, but there was always some sort of comfort in knowing that there were people around me acknowledging autism month. It could be as simple as driving by a front yard and seeing an autism awareness sign stuck into the grass, or an EFMP sign talking about autism awareness as I came into the gate. There was usually something out of the corner of my eye that acted as the three-finger salute of solidarity that was iconically seen in the film series *The Hunger Games.*

I was checking on a friend last week who is also raising a son with autism, and I noticed she had a dismal post on Facebook. Being concerned about how she was doing, I clicked on the comments, hoping that it would provide more insight into how she was holding up since her son had been suffering from more seizures recently. A friend had posted, "How are you doing? What's going on?" My friend replied, "Nothing. That's the problem." I knew what she meant. Nothing was happening.

April is month of the military child and also Sexual Assault Awareness month, the same month as autism month. Celebrating military children and providing awareness to sexual assault are very important, but selfishly I ask, "What about us? What about autism? Is it not important anymore?" At Fort Jackson, I have not seen one event to discuss autism awareness. There isn't even a virtual walk. I've looked on the Fort Jackson Facebook ACS page and there wasn't acknowledgment of April 2nd being World Autism Awareness Day. Posts have only consisted of this month being "Month of the Military Child" and "Sexual Assault Awareness Month."

For the past week, I kept telling myself, "Shelly, you're overreacting. The world does not revolve around autism." The more I thought about it, I'm not overreacting, because it's not just our family. There are thousands of families just like mine who are living daily with autism, whether it involves their child or themselves. Autism month is not just about awareness, this month is to allow parents to process, grieve, and talk about autism. I brought up the issue to Mark, my husband, and he responded, "I know! They're taking our month! There are another eleven months to choose from. Why our month?"

Tiffany Martschink is an Army veteran and is on the spectrum. She has a podcast entitled, "Mettle of Honor" to discuss military issues, as well as autism. Podcasts like hers are a way for people to connect who have shared experiences, and to allow people to discuss topics, such as access to care issues, PTSD, transitions, and overall military culture. I had the opportunity to speak with her this past week about being a military spouse raising a child with autism. She was a gifted interviewer because she quickly gained my trust. I talked about experiences and situations I had not discussed in quite some time. As a writer, I will write about the experience then let it go. This is the way I process my feelings. Tiffany created an opportunity for me not just to write about it, but to talk about it. For that hour, she provided the opportunity for me to experience the feeling of lighting it up blue. I realized that April is not just Autism Awareness month to educate others around us about autism, it gives our families a time for reflection. April gives our families validation for our hardship and a time where it is safe to talk about it.

> "Celebrating military children and providing awareness to sexual assault are very important, but selfishly I ask, 'What about us? What about autism? Is it not important anymore?'"

Last April 1st, my husband rigged a light to our porch and screwed a blue light in our lamp by the front door so the color blue would shine from our porch. I was prepared to be the only blue light in our neighborhood. After my weekend hike with my friend, Tara, she looked over at my porch and said, "Why do you have a blue light rigged on your porch?" I told her about April being Autism Awareness Month and I offered her a blue light if she was interested in shining it on her porch. A few minutes later, her husband, Frank, texted me, "Give me one of those blue lights!"

The next day, I was driving back into the neighborhood after taking Broden to clinic. I looked over at their house on the corner and saw their blue light shining bright from their porch, giving me the three-finger salute of solidarity. They see us. •

PUZZLES & CAMO

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

ADAPTIVE/SPECIAL NEEDS BEDS

KAYSERBETTEN

P: 800-574-7880
E: ruthann@kayserbettenus.com
W: www.kayserbettenus.com

Designed to allow the child to be part of the surroundings while being safe and secure in their bed.

BENCHCRAFTED FURNITURE

MAINE WOODWORKS

W: www.mainewoodworks.org
E: info@mainewoodworks.org
P: 207-887-1989

A nonprofit organization that supports individuals with disabilities, Maine Woodworks employs an integrated workforce, made up of people both with and without disabilities.

CLEANING/SANITIZING SOLUTIONS

BANTEC SANITIZING

www.bantec.store.com

Easy to use disinfecting products and safe, environmentally friendly hygiene strategies that are efficient and cost effective.

FINANCIAL PLANNING/ ESTATE PLANNING/ INSURANCE

MASS MUTUAL SPECIALCARE

www.massmutual.com/specialcare

Financial planning products and services by a company that cares.

FINANCIAL PLANNING/ EDUCATION

THE AMERICAN COLLEGE OF FINANCIAL SERVICES

www.theamericancollege.edu

A private college focused on professional training for financial practitioners

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LJS ELECTRIC

www.ljselectric.com

Home automation products and devices professionally installed.

NON-PROFIT

IRENE AND ERIC SIMON BRAIN RESEARCH FOUNDATION

www.iesbrainresearch.org

Helping to further research and find answers to addiction, pain and other brain diseases and disorders.

SCHOOLS/CAMPS/RESIDENCES

THRESHOLD PROGRAM AT LESLEY UNIVERSITY

Cambridge, MD
W: www.Lesley.edu/threshold
P: 800-999-1959 ext. 8181; or 617-349-8181
E: threshold@lesley.edu

A two-year, on-campus college experience for students with diverse learning challenges.

Coronavirus Disease 2019

COVID-19

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

How Do You Practice Social Distancing?

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

To learn more about TRICARE and COVID-19, visit:

www.tricare.mil/coronavirus

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