mélange

April 2021

Accessibility for All



Rick Hansen

Envisioning a
BARRIER-FREE World

Colletty's Cookies

Collette Divitto has all the right ingredients to be a leader

Epilepsy South Africa

Serving the needs of the epilepsy population, nationwide

"He's autistic but accept him the way he is"

Maya Pandt, Parent Advocate

Charmaine Werth

Creating Accessible Caribbean Outdoor Spaces

Yosef Rubinoff

"Never Give Up"

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9 772563 569003

To Table of Contents

AUTISM AWARENESS

2 April

World Autism Awareness Day

April - Autism Awareness Month

An attempt to create awareness, understanding and acceptance of people with autism



Contents



Cover Story

Canada. Rick Hansen
Rick Hansen Foundation
Envisioning a barrier-free world
Photo Credit: The Rick Hansen Foundation



Tamara Taggart
Canada. Down Syndrome Parent Advocate



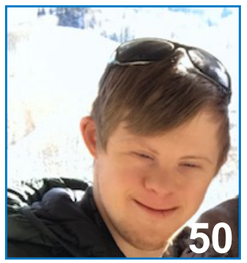
Maayan Ziv
Canada. Universal accessibility through her lens. Founder, CEO AccessNow



Maya Pandt
St. Eustatius. Autism Parent Advocate



Charmaine Werth
Antigua. Creating accessible Caribbean spaces



Connor Long
USA. Actor, Advocate, Athlete



Jamie Lassner
USA. Friends of Access Israel



Yosef Rubinoff
Israel. "Never Give Up"



Patrick Lafayette
Jamaica. Blind Radio Broadcaster



Kenneth Suratt
Trinidad & Tobago. Blind Advocate

8 Interview Tips
How to conduct a job interview with candidates who have autism

30 Diversity & Inclusion
Six things to consider

42 Easter Seals Canada
Programs of British Columbia & the Yukon

43 The Smell of Happiness
Bottling the smell of happpiness to help treat depression

65 Caribbean Recipe
"Creole Lobster" by partially blind Chef Saheli

66 Raising Nathan
by Christine Staple-Ebanks, Special Needs Parent Advocate, Jamaica

76 Tips for Travelling with an Autistic Child
It can be challenging but keep these tips in mind

82 Times They are a-changing
2021 - a Pivot Year for Accessible Restrooms in England, By Avesco

86 Bender Consulting
Finding competitive employment for people living with disabilities

92 Desirability and Disability
Role of adaptive lingerie and community
By Intimately

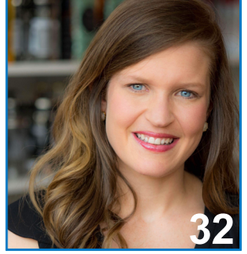
98 Accessible Dubai
Return trip better than the first

110 Accessible Indonesia
Candid observations for wheelchair users

114 En Route to a Fully Accessible Barbados
Accessibility – full accessibility – just makes sense

130 Epilepsy South Africa
Programs, Services, Myths, Management

136 FONHARE, Haiti
In pursuit of a permanent home



Gretchen Kingma
USA. A marriage between occupational therapy and real estate

Lil E Cafe
Canada.
Inclusive Employer



Tactile Images
USA. Art the blind can experience



Colletty's Cookies
USA. Collette Divitto. All the right ingredients to be a leader

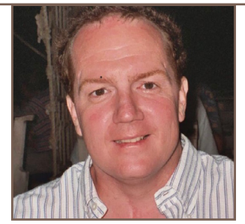




Expo 2020 Dubai
DUBAI. Dr. Jennifer Camulli talks about autism, inclusion and Expo 2020 Dubai

Chef Seth Saheli
ST. KITTS/NEVIS. Partially blind and creating your next recipe





Fred Maahs, Jr.

Editor's Note

Welcome to our April issue of
Melange Accessibility for All, magazine.

The past twelve months have been difficult for all of us around the world but it seems we are finally seeing hope on the horizon with the COVID -19 vaccinations. As we either receive or wait for the vaccinations, we must continue to be smart and diligent with our safety. We must continue to wear our masks and continue to keep a safe physical distance until we have heard from the scientists that it is completely safe to do otherwise. If we approach this wisely and listen to the experts, we will make it through this unprecedented epidemic – together. So, let's be a little more patient and continue to be safe, and soon our businesses will flourish, economies will bounce back, travel will resume, and I believe the job market will be better for people with disabilities.

In this issue of Mélange, you will read about people and organizations from all over the world – each making a difference in the lives of people with disabilities. And, everyone at Mélange wants to thank you, our readers, for your continued support and readership!

We want to make it all real, all relevant, and we certainly appreciate your thoughts. Let us know if you have a product you want us to try and write about. If you have an idea for an article, or you want to invite us to visit your city, country, resort, or place of interest so that we can write about it and share it with our audience, please let us know at fmaahs@readmelange.com.

Finally, I wanted to acknowledge that we recently lost a dear friend colleague in the disability community, Joanne Peterson. Joanne was an entrepreneur, an author, and a tireless disability advocate. She was the CEO of Abator and Co-Founder of 360 Access. You may remember that we featured an article about Joanne and her business partner, Madonna Long, in our inaugural, October 2020 issue of Mélange, Accessibility for All about their work at 360 Access. Joanne meant so much to so many. She was always willing to collaborate on projects and share ideas and information. She was the consummate "champion" for people with disabilities. I was fortunate to know her and to serve on the 360 Access Advisory Board. Joanne will be missed.

Thank you for reading.

Warm regards,

Fred J Maahs Jr @FredMaahs

Fred J. Maahs, Jr. is an internationally-renown disability and civil rights champion who believes in and advocates for the rights and access for all! A recognized leader and former corporate executive, he's also an International Keynote speaker, collaborator, and an international accessibility travel expert.

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We try to present information that is current and accurate, but errors can occur. If you've found an error in the magazine, please
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How to conduct job interviews with candidates who have autism

The unemployment and underemployment of capable workers with autism is a well-documented phenomenon, as a British study showed.

Employers are gradually getting better at recognizing the value of including neurodiverse people in their organizations, and information about accommodation strategies is starting to become more readily available.

That said, these accommodations aren't helpful to workers if they are unable to land a job in the first place. Recruitment and selection practices can inadvertently negatively impact candidates with autism.

The job interview in particular can be problematic since people with autism often struggle to understand unstated communication and social norms. Their difficulties in these areas can result in poor ratings during interviews, even when the candidate would be an excellent fit for the job, which puts both the candidate and employer at a disadvantage.

Some simple tactics can help lessen the likelihood of this happening.

Interview setting

People with autism often have sensory processing issues as well as difficulties understanding body language, facial expressions, vocal tone and social norms.

Panel interviews in which multiple people interview the candidate at once magnify these issues since the candidate has to focus on several people's non-verbal and verbal communication at once. This is both challenging and exhausting for many with autism, resulting in under performance.

Employers often prefer panel interviews over individual interviews, however, because they have been proven to minimize non-conscious biases in hiring. But organizations can achieve the same goal with sequential interviews.

During sequential interviews, candidates see multiple interviewers, but not all at the same time. Candidates with autism can be more fairly assessed using this method, although caution needs to be taken not to schedule too many interviews too closely together. Having interviews on separate days would be ideal when practical.

The location of the interview can also be important. Employers should select quiet spaces without visual distractions, heavy scents or fluorescent lighting. Avoid interviews conducted over meals since managing the unspoken etiquette of dining can be a substantial distraction for those with autism.

Question types

The nature of the questions asked in interviews can also systematically disadvantage candidates with autism. Avoid vague questions or trendy pop-psychology questions that have no discernible connection to job tasks and responsibilities.

For example, questions like: "If you could be any animal, what animal would you be and why?" are simply bewildering for people with autism (and many others). Also avoid testing skills obliquely.

Some employers use questions like: "How many red jelly beans are in this jar?" and expect a candidate to demonstrate their numerical reasoning and estimation skills. A person with autism may take this question very literally, however, and believe that the only way to answer is to actually count the beans. Instead, test relevant job skills directly using objective, scientifically validated tests.

It's also important to avoid overly socially biased (people-pleasing) questions, especially when they are unrelated to job tasks and context. Don't ask what someone else might do or think ("What would your supervisor say about you," for example). Ask more direct questions — people with autism respond well to questions related to things they have actually experienced.

Phrase behavioural questions, such as "tell me about a time you experienced a disagreement about process flow with a coworker and how you handled it" accordingly. A hypothetical situational scenario can be tough. Avoid any question that starts with "imagine;" instead use "describe a time."

General communication

There are also some general communication guidelines to observe when interviewing people with autism. Avoid the use of confusing language that could be taken literally (for example, "land a job").

Be aware that norms around sensitive matters such as salary negotiations may not be clear, so the candidate may not react as "expected." That should not impact a candidate's interview score unless salary negotiations are actually part of the job description for the job they're applying for.

Be aware that a subset of people with autism are highly adept at noticing micro expressions, the very quick expressions that flit across someone's face before they "rearrange" into a socially acceptable reaction. The people able to perceive this, however, are often unaware that they are supposed to ignore those expressions and respond to the "public face" instead. This can lead to social awkwardness.

Once again, that should not impact the candidate's interview score unless understanding social nuances is a key job requirement.

These practices can help employers hire highly capable skilled workers with autism.

And that means organizations can positively impact their bottom line and competitiveness while also achieving social justice and equity goals — a worthwhile effort indeed.

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Associate Professor, Business and Administration, University of Winnipeg

The author would like to acknowledge the important contributions of Tracy Powell-Rudy and Marcia Scheiner of Integrate Autism Employment Advisors, an organization that helps identify, recruit, and retain qualified professionals on the autism spectrum, to this research.

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Read the *original article*.

To Table of Contents



Tactile image of 'The Tank'

Tactile Installation 'George Washington Crossing the Delaware'

Tactile

Tactile Images



Experiencing a tactile image of the Mona Lisa



Experiencing a tactile photograph at an exhibition



Tactile installation of 'Mask, Bill Scannell', © Kurt Weston



Experiencing a tactile photograph at an exhibition

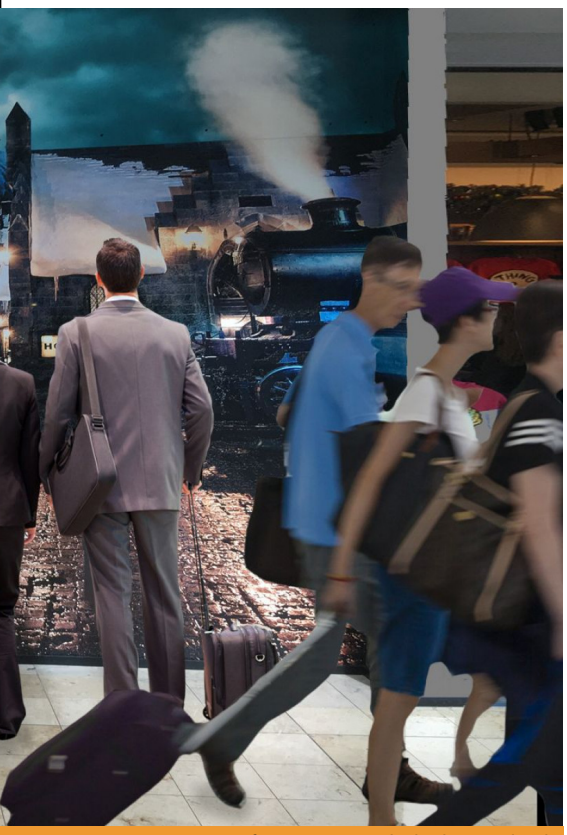


During his impressive photojournalistic career spanning 40 years, veteran photographer John Olson has captured countless moments in time, memorialized by expert photography. At just 21 years old, he joined the staff of LIFE magazine, the youngest they have ever hired. Throughout his career at the magazine and later, his unique perspective and keen eye have allowed him to engage audiences with compelling storytelling imagery.

Photography and art take viewers on exciting journeys that were previously inaccessible to the blind without sighted assistance. As a photographer, John knew the depth of feelings photography evoked. Although he did not know anyone who was blind, he thought of the many experiences they were missing by not seeing these images.

To Table of Contents

art the blind can experience



Harry Potter for NBC Universal - display in Orlando International Airport

Making art accessible to the blind became his goal. In 2008 with his wife, Nancy, 3DPhotoWorks was founded where tactile printing enables the blind and disabled to enjoy art through touch and sensory stimulation. Tactile Images, an entity of 3DPhotoWorks, was formed in January 2021 in partnership with Getty Images and the National Federation of the Blind. Through this partnership, tactile images can now be made available to the blind internationally.

The liberating tactile image experience, further enhanced by audio and smell, takes users on an adventure. As their hand glides over the audio coordinate embedded in the tactile image, it describes what is being touched. Other sensors describe the entire piece. For example, for *'The Battle of Hue,'* the audio includes recordings of the US marines featured in each photograph, talking about the battle and their time in the Vietnam War. Audio describes what is occurring, but it also provides a unique narrative. All of the company's tactile image displays have the option of emitting smells, which helps to enhance the kinesthetic experience. With their large piece of *'George Washington Crossing the Delaware'* in addition to *feeling* the surface of the image and *hearing* the story of what occurred, you can also *smell* gunpowder, thereby deepening the sensory adventure.

Art is being brought to the blind and disabled by museums and institutions around the United States through Tactile Images' Travelling Exhibitions which are also available to countries worldwide. The pieces in each exhibition are either their own or created in affiliation with Getty Images. They are available for purchase by museums, science centers, libraries, and government programs that serve the disabled.

Tactile Images' first major museum exhibition was entitled *'Sight Unseen'* at the Canadian Museum for Human Rights in Winnipeg. This exhibition featured artwork by artists who were blind or low vision.

Many institutions use their own imagery and combine it with images from Getty. Over 45 million images are available to be translated into tactile prints.

The collection of images can be easily accessed through Tactile Images website at: www.tactileimages.com
Any image can be turned into a tactile print. These include, but are not limited to:

- **Architectural Renderings**
- **Diagrams**
- **Drawings**
- **Paintings**
- **Collages**
- **Photographs**
- **Schematics**
- **Maps**
- **Scientific and mathematical formulae**
- **Historical Documents and Manuscripts**



Patrick Lafayette

Patrick Lafayette

Blindness: A Different Type of InSight

"To do something for yourself is one of the greatest things you could ever do. Now, I can express myself! I have so much that I've always wanted to express... I'm like a volcano. I'm like Pelee or Mount Etna. I'm about ready to erupt!"

So begins the soulful voice of Patrick Lafayette, veteran radio broadcaster and singer, in a promotional video for Apple's visual impairment assistive technology. In the video we see him soothing his radio audience, enjoying a meal with his family, and working his magic as a radio broadcaster. Patrick's feature in this short production represents a confluence of some key elements in his inspiring and impactful life thus far: an unmatched talent in radio broadcasting, the mastery of technology in his personal and professional life, and a lifelong desire to share what he learns to uplift others.

It all started at the age of 12 with an eye injury during a "stickball" (cricket) game. Fearing further damage and in light of the ensuing eye trauma, his parents restricted his movement outside the home, even to the point of pulling him out of school. During this time, he became very acquainted with radio and filled his time calling in to radio programs, winning competition after competition until the stations banned him from participating.

At the age of 16 a few years later, a detached retina from a diving incident resulted in further vision loss. Local doctors operated to no avail and eight months later, a consultation with New York State Medical Centre doctors confirmed his devastating new reality: total vision loss. He now faced a choice between remaining in New York to do rehabilitation and returning to Jamaica, where he would have to start over as a blind person. His parents made the difficult decision to let him stay in New York, where he was rehabilitated, earned his GED, and completed a bachelor's degree in communication arts. He returned to Jamaica in 1983 to intern with Radio Jamaica, an experience that would cast him into the role of industry gamechanger.

"I have had the experience where a track was about to...end and I just reached into my pack for another disc, and it was the perfect fit."

It was in these early internship days that Patrick's raw talent for broadcasting started showing itself. Originally assigned to Radio Jamaica's (FM department) 12am-5am slot – the "safe" one should there be any mishaps – Patrick's fresh new style soon forced management to move him to the prime 3pm-6pm slot. He was resonating with the young audience through the unheard elements of rapping, mixing, scratching, DJing, etc. He was also introducing listeners to foreign artists and different music styles and attracting a steady flow of sponsorship. This moved Radio Jamaica to shift its focus from AM (then the primary source of information) to FM and in turn, precipitated the complete change of Jamaica's musical landscape.

Over time, Patrick solidified his name in Jamaican radio through work with several radio stations, two of which he co-founded (KLAS FM in 1989 and Kool FM in 2001). He performed in various functions including announcer, engineer, creative director, show host, and operations coordinator. He produced audio content for over 50 stations in Europe and the US, the Jamaican government, and VP Records, the largest independent reggae label in the world. Further evidence of his creativity was the single-handed production of the audio book series *Mas Joe - The Christmas Adventure*, a humorous story of Santa's elves saving Christmas, of which the effects and all 11 character voices were done by him. In 2005 he resigned as station manager at Kool 97 FM to start his own production company, Twin Audio Network.

In 2014, Patrick started Chris Mix Radio, an internet radio station named for his brother Chris who had passed away in 2013. Chris Mix Radio "feed[s] Jamaica with diaspora information" through music and audio biographies of prominent Jamaican artists that Patrick has met through his work. The station forms part of the Worldwide Radio Network, a network he created with other radio broadcasters around the world and in which the stations carry each other's signals for maximum reach.



Patrick at console for album launch

Click here for the audio of:

Click here for the audio of:
Mas Joe - The Christmas Adventure

"If I get the tools and . . . access, I can compete . . .

Patrick is the true embodiment of this phrase, from his natural love of technology to his competence in exploiting it as a life-changing force. Truly pivotal was his introduction to Job Access With Speech (JAWS), the screen-reading technology that allowed him to access the internet and communicate with others: he could now fully move in the online world. He built his own computer and bulletin board system (BBS) and in a short break from broadcasting, qualified himself and gained experience as an IT professional. He worked as a computer analyst at Communications Associates (Miami – 1990-1992) and then completed certifications in WordPerfect and Lotus. As a senior analyst at Chuckles Resort in Negril, Jamaica, he established the company network, organized the reservation system, and conducted staff training.

Even more critical to his personal and professional success, however, was his discovery of mobile phone assistive technology like voice-overs, first on the Nokia phone and then later on the I-Phone. He dug in and mastered apps like Tap Tap See to optimize daily living and Logic Pro to enhance his recording projects, all the while unwittingly catching the attention of a certain tech giant. He was duly surprised when, in 2017, Apple approached him to feature in a brief promotional video to be aired on Global Accessibility Day that year. The "Like a Volcano" video formed the inspiration for his own album Volcano (launched in 2019), a collaboration with other visually impaired musicians around the world. For yet another Apple event, he demonstrated his use of the iPhone and Anchor, an accessible app for creating podcasts and doing broadcasting projects, and debuted a song from the Volcano album. For Global Accessibility Day in 2019, he was flown to Apple Park to perform some of his music.

"As soon as I get it, I give it."

In the true style of a groundbreaker, Patrick has always valued giving back to his beloved Jamaica. He feels responsible for sharing the knowledge he's gained, and this is exactly what he did with each new technology tool he learned. As soon as he had mastered JAWS, he returned to Jamaica to offer free classes through the Society for the Blind. He returned again on successive occasions to teach on Nokia voiceover, iPhone technology, and podcasting tools. Several now very prominent Jamaicans attended his classes and others have been inspired to start their own podcasts. With such a track record, Patrick can comfortably claim responsibility for increasing Android and I-Phone usership in Jamaica.

In addition to his work instructing persons with visual impairment, Patrick has been involved with the boards of numerous local organizations representing other disabilities, taught students with combined disabilities how to use computer apps at the Abilities Foundation (Kingston, Jamaica), and mentored people in the computer industry. Understanding the destructive effects of prejudice and alienation, he has also helped to develop counselling programs to help children affected by HIV/AIDS to reestablish their lives.



"…blindness is not the end of your life…it's a gift from God: you get a different kind of insight."

Patrick's life has been a testimony to the fact that while it is understandably difficult to accept a disability at any age, the achievement of dreams and wonders awaits whoever will step out and go for it. He did this very thing at a young age by daring to see past his blindness to develop and share his talent. He embraced the uniqueness of his perspective to blaze trails and used the resources available to change mindsets. It was quite fitting, then, for the True Tribute Organization (New York) in 2018 to recognize him for his contribution to Jamaican culture and music; above all else, it confirmed that "the whole idea is to employ, integrate, and give access [and that]….once we get the access, we can rock!"

Living And Leading With Confidence

Kenneth Suratt

Kenneth Suratt was born on the Caribbean island of Trinidad in 1968 with congenital cataracts. As a child, he had low vision. Attending school in the 1960's, he devised a strategy that allowed him to capture what was written by the teachers on the chalk board. He sat really close to the front of the class and whatever he could not see on the chalkboard, his friends would read it out to him. When he was eight years old, his teacher informed his parents about the severity of his condition and advised that his eyes should get tested. Kenneth did not think that was necessary because the only hindrance he perceived at that time was simply his inability to copy what was written on the chalkboard in class and, with his friends, he had found a way to make that work! However, his parents took him to the ophthalmologist and based on the extent of the low vision diagnosis, he was sent to the School for Blind Children on the island.



He was just eight years old when he was admitted to this institution that housed and taught children who were blind and had low vision. He describes this as one of the most traumatic experiences of his life, remembering quite vividly the day his mother dropped him off at the boarding school. While he was playing with his new-found friends, she quickly slipped away to lessen the trauma of the separation. Kenneth then saw his family only three times per year when school was on vacation. When he was 13 years old, as part of an integrated program to have children from the School for Blind Children included in main stream education, Kenneth started attending Queen's Royal College high school. While there, at the age of 14, he completely lost his sight.

Kenneth remembers waking up one morning seeing a range of different colours at the corner of his eyes. Within one week, the colours looked 'broken'. He was diagnosed with retinal detachment. Kenneth travelled to Miami and England hoping surgery could be performed to correct the situation, but nothing could be done so he returned to Trinidad, blind and emotionally broken. For a while, he pretended he was still able to see and continued interacting with his friends at the integrated high school as best he could, bumping into things as he went along. Used to him being of low vision, this was initially not startling to his friends, but they eventually realized that he was now totally blind. This realization that others now knew of his blindness sharply jolted him into his new reality. He could not cope, was scared to move around and the school had no one to counsel him – the best counselling he received was from his friends. He was not familiar with braille, as he previously had a system with his friends that allowed him to read/see sufficiently well with their help. He now had to readjust, learn braille and figure out how to live from then onwards as a blind person.

It was not an easy journey. Kenneth went through a period of depression as he attempted to adjust to the new life and navigate his way through the emotional and physical darkness. At that time, music was his only solace. Playing his guitar and writing songs through which he vocalized the raw emotional turmoil he was enduring, gave him short-lived comfort. Many sad songs were written during that period, but Kenneth was resilient. Time progressed and he finished high school, then enrolled at Trinidad's College of Science, Technology and Applied Arts. He completed an Associate's Degree in Business Administration and today is the Executive Officer of the Trinidad & Tobago Blind Welfare Association (TTBWA). He is currently pursuing a Human Resources degree.

Kenneth credits his love for music as the lifeline that helped him to reintegrate himself into society. In 1991 with five other blind persons, he formed a band and travelled around the island performing at weddings and other events. Visionary Sound was the first all-blind band in Trinidad & Tobago and their popularity quickly grew, with them becoming the must-haves at many social functions. The band has since broken up as the members got married and moved on but its positive impact remains.

Kenneth has and continues to be a vocal advocate. In 1994, he was awarded the National Youth Award for Special Education. He was an integral part of the team which in 2006, won the case at the Privy Council for the establishment of an Equal Opportunity Commission in Trinidad & Tobago. In 2020, his advocacy led to the amendment of the Copyright Act to make printed material accessible for the print-disabled. He also advocated for the Trinidad & Tobago currency to be changed from cotton to polymer notes so that tactile features can be added allowing persons who are blind to independently identify their money.

Kenneth believes that life for the blind in Trinidad and Tobago today is much easier than it was for him as a child – this he attributes to modern technology. He is heartened to see blind children are integrated into the regular school system and doing well, although improvements are needed in the way Math and Science are taught, especially now during Covid where online teaching/learning is used. The use of Braille is not widespread throughout Trinidad & Tobago, but now that it is in digital format and no longer bulky, Kenneth and the organization he leads are encouraging its use. They undertake the conversion of restaurant menus into braille, go to people's homes to put tactile buttons on their appliances, teach them to use technology, how to navigate websites and also provide advice, as needed.

To date, Kenneth says, the Government of Trinidad & Tobago is the main employer of the blind. The private sector has not yet embraced the inclusive employment concept resulting in some blind persons turning to self-employment. Kenneth believes there is a lot to be done on the island including the built environment which needs to be made accessible as it is not easy for the blind to get around safely in their communities. Many obstacles exist and navigating the outdoors for a blind person presents numerous challenges. Stray dogs, uneven pavements, hanging branches etc., are all hazards for a cane user. There are no legislations in place to enforce compliance to building standards which poses a serious threat to the independence of the aging population and people with disabilities. TTBWA, in their four branches, is therefore committed to continued advocacy, training the blind to advocate for themselves and working with government to implement the United Nations Charter on the Rights of Persons with Disabilities (UNCRPD) to build an all-inclusive Trinidad & Tobago.

Kenneth's Music

"Die in your arms" | "Push your flag"



All Photography in this feature credited to the Rick Hansen Foundation

Rick Hansen

Founder of the Vancouver, Canada-based Rick Hansen Foundation, Rick is passionate in his pursuit of a better life for people with disabilities. He is well-known for his 1985-1987 Man in Motion World Tour, a 40,000 km wheelchair marathon that covered 34 countries, raising $26 million for Spinal Cord Injury research and to create an accessible, inclusive world..

Mélange sat down with Rick to speak about his Foundation and vision for a world with no barriers.

> I think we need a more sophisticated version of what I did, something to connect the world . . . to create a movement that would capture attention and imagination with global participation, connectivity and sustainability to accelerate progress and grab the interest of the more socially conscious next generation to bring them into the conversation . . .

What was your inspiration for the Man in Motion World Tour?

From my early years, I had no reference to disability. All my life was defined by physical ability as an athlete dreaming of one day being able to represent my country at the Olympic Games. Then, suddenly in 1973, I found myself paralyzed after a car accident and told I'd never walk again. That challenged my internal barriers, attitudes, perceptions and stereotypes. I was handicapped more than I was disabled, by my medical condition, and I had to really fight against that. Role models, mentors and people who have been there before showed me that people can actually still live whole, full lives, in spite of not having the ability to use their legs, or have another type of disability. That internal process made me realize that people with disabilities faced a lot of attitudinal barriers. I was also facing social barriers by family, friends and the community which made it even harder to struggle against. And then, there were the physical barriers. Those were interesting journeys as I went through my life.

Later, travelling the world, representing my country as a Paralympic athlete, everywhere I went I met incredible people. Some had visual, hearing, mobility challenges and they all said the same thing – that they have struggled with their own internal conditions, they fought upstream against attitudinal barriers and when they tried to perform, they had to go through physical barriers, so that experience made me realize that I



Rick at the Great Wall of China

wanted to not complain about my reality, instead I wanted to take some of the lessons that I learned in sports and from the role models that had impacted me on my life's journey, and try to pay it forward. I thought about my athletic challenge, which was at that time a wheelchair marathoner, and then I looked for solutions that might hopefully change attitudes. When I left for my Man in Motion World Tour at the naïve, young age of 27, I thought that maybe I could create a beginning, a global movement. However, I soon realized how large and disconnected the world was, and what a struggle it would be just to try to accomplish the Tour itself, let alone try to build awareness, raise funds and ultimately create a movement.

But there were milestones created on the Tour. Being accepted into China was an incredible one considering that it was an insular country. The warm reception I received was in part due to Deng Pufang, the son of the then Chairman, Deng Xiaoping having received life-saving medical treatment in Canada for his spinal cord injury. He was inspired by the Canadian aspiration of our Charter and Constitution and the shifts of our attitude to people with disabilities. When he returned to China, he wanted to start something significant for their over 70 million people with disabilities. So, he welcomed us into their country.

The idea of people with disabilities being able to not just move out from being a ward of the state, a shut-in or a burden to family but to actually lead and champion a concept that was a radical departure from the status quo, was significant and worthy to be pursued.

How did society perceive disabilities at the time of your injury?

Back in 1973 when I had my injury, if you had a disability, there were not a lot of expectations. I was even told during my rehabilitation that I should not set my sights too high so as not be disappointed. That opinion permeated throughout the entire planet in so many ways. Early pioneers who pushed out in front of me did the heavy lifting, breaking the threshold of possibilities, because at that time, human rights did not really exist. Charters or legislative declarations and the Americans with Disabilities Act was still a fantasy in the seventies. Even when I left on my Man in Motion World Tour, there were still a lot of champions fighting upstream for that, and it wasn't until the 1990's that it happened. In the early 1980's Canada had an incredible constitutional commitment in our Charter of Rights and Freedoms, but the translation of those beautiful words of the Canada that we wanted, and the legislative framework that existed, was still a major mountain to climb.

Very significant levels of progress have happened in the decades since that original, early, crazy start of my Man in Motion World Tour. When you look at the way in which the United Nations has now embedded elements of the Charter of Rights and Freedoms, challenging countries around the world to sign in to the convention, to measure up and report back, this is the result of amazing champions, generations of people who just didn't accept the status quo but believed in equality and found opportunities to fully participate and contribute. They continue to chisel away, breaking down barriers one at a time. We're not fully there yet but I think a tremendous amount has been accomplished.

I believe the digital age has also helped immensely because the world is more connected and stories of ability, potential and examples of a world that we all strive for I think are more easily accessible. It's becoming more commonplace to expect that it is possible and I believe that, plus actual tangible progress is creating an accelerating opportunity, and it is really an exciting time to be involved in this movement because there's tremendous hope for the future.

What do you think can be done to combat the lack of awareness?

It is a large uphill battle for many countries - in Africa, the Caribbean and even in places like the United States or in Canada. There are still very entrenched pockets of resistance and part of it is fundamental, cultural beliefs and old paradigms that have been passed down and they remain rigid until such time as someone shatters that perception. These beliefs are perpetuated by lack of awareness, and the only way we

















can actually address this, in my mind, is by constantly sharing stories that counteract that ignorance.

How can progress be accelerated?

One of the biggest diseases of our world is that there is a community of 1.3 plus billion people with disabilities, boomers and their parents on the planet today - the world's largest minority - yet this community continually hits below its weight. This 'disease' is being fragmented by body parts, by clinical diagnosis and different points of emphasis of all these wonderful organizations working in their very specific purpose-driven missions, but very rarely do we converge on the largest barriers together to create a more powerful case, not just for human rights, which are critical, not just for charity, which is very important, but for the cultural, social and economic imperative that is absolutely vital for the ability of any leader of an organization, business or a country - to serve its citizens well.

The cost of confinement is unsustainable, the human, social, cultural and financial costs are fundamentally unsustainable and any leader who doesn't understand that is being irresponsible and they're not serving their citizens well. It is critical for our communities to start to move together and elevate the case to which transformation seems difficult, and oh so costly to make. They are completely unaware of the fact that there's this incredible wellspring of opportunity when people who have disabling conditions come in and contribute their ability, to increase the fabric of society and drive innovation, products, services and customers, really changing the whole dynamic of a society. I think it's time that we actually turned it around and upped our game and put all of our logic points together in a convenient place and have leaders feel the weight of the community and the weight of the case. I think that will accelerate our progress. Anything we can do to come together at that level is fundamental because we're becoming more and more of a globally connected civil society. We also have to understand the incredible power and opportunity of this digital revolution that's sweeping our globe and be able to reframe and reorganize the way we function.

What part is your Foundation playing to address barriers to people with disabilities?

Our Foundation is like a social entrepreneurial organization where we look at big barriers and then we try to focus and find solutions. We bring experts and resources together, incubate pilots that are tested and then we start to roll them out. We have a vision of these solutions being globally relevant and portable. Ultimately, we work hard as best we can to add value. What we saw in the world of people with disabilities is that there are lots of barriers that are fundamental, but we're a small group so we asked ourselves where can we put our precious energy and try to move the bar? We then felt that the built environment was an area that needed a lot of attention, for two reasons:

(1) There has been progress in the built environment, but the progress was based largely on pockets of legislation and code which were very limited in terms of their viewpoints at the time, and very prescriptive. They did not take into consideration the functionality of a building, after all, buildings are meant for people.

(2) Secondly, there was a heavy focus on relying on people with disabilities and advocates to somehow parachute in on the backend to vote in their perspective, which was by then already too late, and so there was disappointment, human rights lawsuits, compliance-based issues, costly tax on very valuable investment of money and ultimately energy, and conflict to try to fix what should have been done at the beginning.

We researched groups out there to find out if there were any that operated in other sectors that impacted change and yes, there were - energy efficient buildings. They leaped way ahead. Energy-efficient, 'green' buildings are now being constructed and their sustainability benchmark is top of the mark for incentives and accolades – way ahead of accessibility in their buildings, built for people. They took the knowledge that was embedded in the energy advocacy groups and created a universal standard and a curriculum, and then they started getting the curriculum out of just the hands of the advocates and they pushed it upstream into the industry, government and policy. They normalized it and then every architect, engineer or planner that's coming through universities, or is in a big company must be designated in these fields otherwise, they're not relevant.

But if you look at the schools of architecture, there are very few architects being certified in universal inclusive design, and this is a disconnect. As a result, there are systemic barriers due to big misses. It works both ways because when are so prescriptive on code, you can ask for bells and whistles and very specific modifications, but it may sit there and not be

To Table of Contents



utilized because there is no use or market for it at the time. Observing the back and forth between industry, government and advocates, we wanted to change that, so we started this little pilot in Vancouver which got support from the Government of British Columbia and Government. We rolled that out to the entire Province, with over 1,100 buildings being rated, formed an Advisory Group with industry at the table - all the technical experts from the adapted side were also at the table. We created The Rick Hansen Foundation Accessibility Certification which is rolling out across Canada. There are entities in the United States that are starting to look at this, airport authorities internationally and networks of professionals. Our training is online and global so anyone in the world with the prerequisites can take the course and be designated. It is available at seven universities and colleges in Canada, one of them is the global online Athabasca University. The idea is to get it out there, train and designate thousands of professionals in the field, and advocates too, using the same language, measuring the same things and then get that knowledge upstream until this becomes normal and moves into policy with governments, private sector and agencies. In the bidding process, somebody has to be designated on the design team, there must be a provisional rating before you starting construction and then people who touch a project all the way through will actually have that same level of knowledge, so that by the time advocates come together, they're actually able to do what they should, which is look at whatever unique gaps there may be, based on local circumstances and innovation. That's where advocates can provide the best value.

That's our vision and we're just at the baby steps right now with a tremendous team of hard-working people. Lots of challenges exist because this field is very fragmented. There are different levels of legislation and different views about codes, today's standards may become tomorrow's handicaps, but this exists everywhere so the question is, can we move towards a more global standard in this field? Can we consolidate the curriculum and designate people who do business in multiple nations and jurisdictions and give them tools and consistency? Can we give consumers that same level of comfort? Can we measure then start to create an index? That's up to us. I think we could, but we'll see.

Do you think it's time for the next generation to be groomed to step in?

Yes, by an ultimate marathon of social change. I think we do need something, a more sophisticated version of what I did, something to connect the world, to create a movement-based derivative. A combination of something that would capture attention and imagination with global participation, connectivity and sustainability to accelerate progress and capture the interest of the more socially conscious next generation to bring them into the conversation. But within the conversation of diversity and inclusivity, it is still very easy to drop the issue of disability out of the conversation. So, to keep it in there we can inspire ideas that look at the ways barriers can be transformed. For instance, the Nepalese have been so involved in the service of helping people achieve glory on Mount Everest. Wouldn't it be incredible to come together to create the opportunity for a Sherpa, who perhaps has had a spinal cord injury, to summit Mount Everest, leaving a legacy that will help change the world to show that there were no barriers on this earth that could not be crossed? Right now, people may think that's completely impossible, but I believe it is possible. And you could say, why don't we actually get Elon Musk to help someone in a wheelchair go into space, leave their chair at the space station, circumnavigate the world multiple times a day, speaking digitally to billions of people about there being no barriers, and that the future of space is for everyone? This will help to power up a conversation with the youth and every school on the planet, about what this really represents. The world needs imagination and we need to keep breaking barriers in a fundamental way.

> “ . . . why don't we actually get Elon Musk to help someone in a wheelchair go into space, leave their chair at the space station, circumnavigate the world multiple times a day, speaking digitally to billions of people about there being no barriers, and that the future of space is for everyone? This will help to power up a conversation with the youth . . .



How can we get children engaged in the process?

My dream was to be a Physical Education teacher and coach. I went to University and graduated but I didn't go that route because I was distracted by the Tour. The Foundation, however, always had a school program as part of our journey. It is now in about over 5,300 schools with over 12,000 educators registered to use our resources. We have a curriculum that's no charge online, and it can be adapted into the curriculum of each jurisdiction. Nova Scotia's Ministry of Education is one of those that has formally endorsed our curriculum for K to Grade 12. Accessibility and inclusion are the contents. Lesson plans have been specifically crafted for their learning outcomes. Then, we have ambassadors that visit, in-person and digitally, to tell their stories and to bring students real life examples, experiences and other resources they can draw from. This school concept is valuable so I think that's got to be the end game. Schools are a microcosm of communities and we're building attitudes, values and future champions. This is a way for kids to get engaged in the process and normalizing it on the curriculum is a good path to take.

It keeps evolving. We listen to teachers, administrators and the kids and also keep opening up the envelope before various groups and individuals that represent people with disabilities so they feel that it's as much their programs as it is ours. We are only the facilitator of it now.

www.rickhansen.com













As society takes an increasingly open-minded approach towards race, sexuality, gender, disability, age and religion, it is also becoming increasingly essential to understand the difference between true inclusion and true diversity.

Individuals and organisations that attempt to be diverse and inclusive without adequate training/ knowledge, may cause a reverse effect. Unintended harm to unprotected groups may result.

True inclusion means ensuring that diverse and under-represented groups or minorities are included in communities, decision-making processes in a company, in government and in general. Being inclusive means that minorities also have decision-making authority.

But what really is **INCLUSION** and **DIVERSITY**?

Inclusion
A definition of Inclusion: the act of including someone or something as part of a group, a list, etc and ensuring everyone has equal access to resources.

When discussing minority or discriminated groups, inclusion means having practical methods in place to ensure these groups are included in every level of employment, government, education and in the wider society. This can be in the form of recruitment drives, policy changes or changes to company culture.

Diversity
A definition of Diversity: many different types of things or people/a variety of different things or people being included in something.

To embrace diversity, one must include people from different social and ethnic backgrounds, different sexual orientations, gender and also people with disabilities.

The goal of organizations should be to build diverse teams. There have been many studies conducted to understand the benefits of having a diverse team, the results of which have shown improved productivity, progressive brand identity and decreased employee turnover when this is done.

Diversity and inclusion

Diversity and Inclusion should be an ongoing conversation for the betterment of underrepresented groups in society.

All of the themes and issues that undermine minority groups in society cannot be solved with a few recruitment drives, or by holding an awareness month here and there.

It can be solved by addressing systemic blockades and removing them, starting with government policy change, employment restructuring from the top down and introducing effective educational tools in educational institutes.

6 Things To Consider About

Diversity and Inclusion

1. Education & Training
Training provides safe environments for discussion, collaboration and education for all when done effectively. However, having a lack of these three elements can hinder minorities from integrating into groups, primarily those that include the white, able bodied, middle to upper class.

2. Achieving Diversity But Not Inclusion
Diversity can be achieved by hiring minority individuals to authoritative positions in employment, thus diversifying a workforce. However, companies must do this sensitively, so as not to make these hires appear as “diversity hires” or feel like tokens.

3. Tokenism
Some companies make a huge effort to show how diverse or inclusive they are, but to minority groups it can feel like this effort is to meant to fill quotas or to improve public relations. When inclusion reports are released, they can often be numerically-focused rather than human-focused which is often seen as a hollow attempt at chasing cultural trends and not being truly diverse.

4. Leadership
Leadership or upper management roles must also reflect the company’s ideals about diversity and inclusion. Minority groups must hold these positions once qualified, and should not be overlooked. The same also applies for government. Minority groups will feel inspired and empowered by seeing people who look like them in positions of authority and power.

5. Being Heard As Well As Being Seen
When underrepresented groups have reached leadership and management positions, if those individuals still feel that their voice doesn’t count, does this mean their company does not value the voice of minority groups and merely use them to falsely claim their company is inclusive?

6. Have Human Indicators
As much as we like to avoid talking about Diversity & Inclusion in terms of key performance indicators, there should at least be some indicator of how diverse or inclusive a company is. Not by ticking boxes on a form, but by actively speaking to employees on how policy changes and diversity drives are changing the company’s identity. A human approach is the best approach, not numbers.



A Marriage between Occupational Therapy and Real Estate

Gretchen Kingma

Realtor, Occupational Therapist , Accessibility Consultant
Missouri, United States

To Table of Contents

Universal/inclusive designs reduce functional limitations in the built environment. Will you say wheelchair users benefit the most?

No. I truly believe that when universal design is done well, that we all benefit, not just wheelchair users.

Think about the able-bodied mother in her 30's carrying a baby, a toddler and multiple bags of groceries through the front door or the garage entrance. When the thresholds are made minimal, and the stairs are eliminated for entry, this task is made so much easier for the homeowner.

Gretchen is working to release a course focused on how to serve the real estate industry as an occupational therapist.





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Charmaine Werth

Creating Accessible Caribbean Outdoor Spaces

Charmaine Werth is an Interior Designer on the Caribbean island of Antigua & Barbuda where she lives with her architectural designer husband, Kerry. She has a comprehensive and diverse portfolio having managed design projects for hotels, restaurants, ambassadors, heads of state, ministers of government, banks, medical providers, private residences and retail outlets.

Caribbean design, she says, "is like the people - a mix of cultures, a pepperpot, a potpourri, a mélange, if you will. We use bold colours and many materials. We have deep lazy balconies and patios, shutters for protection, shade and accents of colour and, we bring the outdoors in with many windows and doors."

The uniqueness and diversity of that region has provided her with inspiration for the reinterpretation of contemporary Caribbean design.

For the past thirteen years, Charmaine has been living with Multiple Sclerosis and after her diagnosis, started "thinking differently in terms of my designing," she said. Universal design and the creation of accessible, functional spaces became more important as her awareness grew.

On her island, it is difficult for wheelchair users to get around independently. In the capital of St. John's, there are just a few buildings with ramps, and automatic doors for easy entry are also few. Someone will hold a door open for you, but entry without assistance is not possible in many cases for wheelchairs. Villages and communities in the outer parishes are not wheelchair friendly. Many of the hotels on the island may have accessible rooms but few can be considered fully accessible. Charmaine admits there is a lot to be done in the built environment on her island as it relates to accessible spaces, and she too had to make adjustments in her own home.

"When I was diagnosed with MS, I had to renovate my bathroom for a walk-in shower. I wasn't using a wheelchair but I had difficulty walking and I needed to sit in the shower. I didn't want my bathtub to be in my shower space, so I had to separate them - I basically designed a wet room. I had grab bars installed - and it all looked beautiful, so an accessible bathroom can still be compliant while aesthetically pleasing if you're thoughtful enough about it."



Charmaine thinks safe and functional kitchens and bathrooms should be in the design of every home, with wheelchair users, the blind, people with other disabilities and seniors being the focus. She also believes the outdoors can be made accessible and esthetically pleasing. In the Caribbean, outdoor living can be effortlessly embraced as that region's climate ensures that space can be enjoyed all year round. Charmaine blurs the lines between the interior and the exterior, subtly bringing the outside in as well taking the inside outside. Interior furniture is used outside and vice versa; courtyards are covered with transparent roofing to preserve the ability to still enjoy the sunshine, sky and clouds while protecting furniture from rain. Interior design smoothly transitions to the outdoors with trees, plants and flowers incorporated into a setting that looks good and is also therapeutic.

"We've recreated this outdoor spirit in our home," Charmaine shared, "we have several different outside 'rooms': a couple of secluded areas for quiet contemplation; another that is hidden away and embraced by tropical greenery; and then a couple of larger spaces for lounging, dining, entertaining, chilling and listening to music. The outside is an extension of the inside, which in turn is framed by the jaw dropping seascape." And it is all accessible to a wheelchair user as needed.

Seniors in the Caribbean tend to age in place, and as family members try to make a home as safe and comfortable as possible, accessible outdoor living spaces becomes relevant, not only for its esthetic qualities but also for the emotional benefit it brings. Charmaine remembers working remotely on the home of her friend's parents who lives on a nearby island. Mom had dementia so it was important to not change things around that much and she was also using a walker. Clean and uncluttered was needed and that was accomplished, but the most fulfilling was the outdoor space filled with vibrant flowers through which mom was able to navigate safely with her walker! The people of the Caribbean love their gardens. Because of the pandemic with everyone being at home now more than ever, they want to enjoy their outdoor living, so Charmaine is improving outdoor spaces on the island - balconies, porches, courtyards and terraces are being made pleasing to the eyes and also accessible whenever possible. One of the places on the island where accessible outdoor relaxing space and nature combine, and one which people with disabilities can enjoy, is Agave Gardens. Charmaine's friend, Barbara Japal, is the owner of this horticultural destination on Antigua & Barbuda – a colourful center for therapeutic experiences in an oasis of calm. On Charmaine's advice, Agave Gardens now accommodates wheelchair users and has comfortable walking paths for those with other mobility issues. This center serves as a location, and relaxation through gardening. Workshops are conducted on floral arranging, back yard gardening and seed collecting. They have a 'Seed Bank', which aids food security by collecting and storing seeds for local farmers and gardeners. Having embraced accessibility for all, any visitor can enjoy this space while sipping on a glass of Agave Gardens' signature Lemon Grass Iced Tea.


Charmaine's home


Charmaine's home


Agave Gardens



Agave Gardens


Agave Gardens

Charmaine's design expertise was also used on Antigua's first speech and language therapy clinic, a project which was very dear to her. Center for the Holistic Advancement of Therapeutic Services (CHATS) is a happy, colourful yet calming space.

As Charmaine and her husband consult on new projects, universal design is an integral part of each conversation. Young couples are encouraged to think twenty or thirty years ahead. "A parent may move in," Charmaine says "because that's happening a lot now. Younger people who are building homes have to think about their parents, as it is becoming more common to have multi-generational homes which means that you're not only designing for the young client but you're also designing for the client's parents and children." Charmaine is heartened that nine out of ten times their advice is accepted which "is good because it's an expensive task to have to redo a house just to make it easier to live in."

If you live in a place where the outdoors can be blended into your living space, give it a try. Let nature speak in your 'outside room' and think of accessibility.

To Table of Contents

Easter Seals Canada

Inspired by the formation of the National Society for Crippled Children (later Easterseals) in the US three years earlier, Easter Seals in Canada had its beginnings in the province of Ontario on November 28, 1922, when 10 representatives from seven Rotary Clubs throughout the province came together to form the Ontario Society for Crippled Children (later Easter Seals Ontario). As was the case with their US counterpart, this organization's concern was the lack of services and resources available to children with physical disabilities, and its goals were to ensure adequate treatment and raise public awareness about the needs of these children.

Over the next 34 years, similar organizations that would eventually become part of the Easter Seals family were established across Canada. In 1937, the Ontario Government turned to Easter Seals for expert assistance following a devastating poliomyelitis (polio) outbreak. That same year, Easter Seals in both Ontario and Nova Scotia opened the first Canadian adaptive camps for children with physical disabilities.

Today, Easter Seals and its ten independently governed provincial affiliate organizations have offices and provide programs and services to people living with disabilities in provinces and territories all across Canada, and plans are well underway to celebrate Easter Seals' 100th anniversary in 2022.

Easter Seals

British Columbia and the Yukon

PROGRAMS AND SERVICES

Adult and Parent Programs: Learning and Respite Opportunities and programs for both parents and caregivers, and for adults with disabilities, to connect, learn, and have respite. Throughout the year, there are workshops on topics like finance, and parent nights to discuss current challenges and provide connection with each other.

Easter Seals House: Since 1955, families from all over BC and Yukon have stayed at Easter Seals House while their child or loved one receives care and treatment at nearby medical facilities. Easter Seals House also has also provided a Respite Program for parents and caregivers during the COVID-19 pandemic.

Facility Rentals: Easter Seals has three locations with fully accessible facilities throughout BC, with beach-front property to secluded forests. Each site is ideal for conferences, school groups, church groups, weddings, outdoor education, weekend retreats, day programs and family reunions. All locations are available to rent throughout the year, and rental dollars go directly to support Easter Seals Summer Camps for children and adults with diverse abilities.

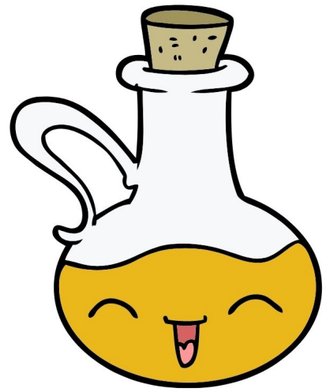
Post-Secondary Educational Awards: A number of educational awards have been established and are available to help benefit youth with disabilities looking to pursue post-secondary educations. These awards are administered by the postsecondary schools, with information on criteria and eligibility available directly from the schools.

Easter Seals Timbres de Pâques

www.eastersealsbcy.ca

Bottling the smell of happiness to help treat depression

It may sound like something out of a fantasy movie, but scientists hope to be able to bottle the smell of happiness so it can be used to help people with phobias or depression.



by Alex Whiting

Our bodies produce different scents when we feel happy or afraid. These so-called chemosignals – which are in fact odourless – are believed to trigger happiness or fear in others. It is one of the ways smell impacts people's social interactions.

'It's like an emotional contagion. If I feel fear, my body odour will be smelt by people around me and they may start to feel fear themselves, unconsciously,' said Enzo Pasquale Scilingo, a professor at the Department of Information Engineering at the University of Pisa, Italy.

Similarly, the smell of happiness can inspire a positive state in other people, says Prof. Scilingo.

'If we had a spray of happiness … If we can find some odour which can induce a happy state – or a general positive state – I think we can help many, many people,' Prof. Scilingo said.

He hopes scientists can produce one within a few years. This could be particularly important in the aftermath of the Covid-19 pandemic, with cases of depression rising especially among young people.

'I don't want to say having this spray will (cure) people, but I think it's a very beautiful contribution,' Prof. Scilingo said.

SWEAT

He is coordinating a project called POTION which is researching these chemosignals. The researchers use videos to induce fear or happiness in people, and then collect their sweat to analyse which chemical compounds are released with each emotion.

'The next step is to synthesise the odours and … investigate how they induce emotions in others,' said Prof. Scilingo.

Eventually, fear odours and people's responses to them could be used to help psychiatrists understand more about different aspects of phobias and depression. And happiness odours could be used to help in treatment.

'If we can use the odour of happiness in addition to the usual treatment for phobias or depression, we (could) increase the efficacy of the therapy,' said Prof. Scilingo.

The POTION researchers are also investigating how odours impact people's social interactions, and sense of inclusion or exclusion from others.

Previous research has found that a person's emotional state can influence how they respond to other people – and how others respond to them, Prof. Scilingo says. Someone feeling fear is less likely to approach or trust people, and others are likely to be wary of them. And the reverse is true for happiness – the happier someone is, the more likely they are both to trust others and to attract them, says Prof. Scilingo.

MAMMALS

In mammals, the sense of smell is uniquely linked to the part of the brain associated with emotions and the creation of memories, says Dr Lisa Roux, researcher at the Interdisciplinary Institute for Neuroscience in France.

Smell is important for recognition between people. A mother can recognise the smell of her child, for example, and this may be an important part of bonding, she said.

'We humans use our sense of smell more than we think. It's more unconscious, and a little bit taboo – we are not very comfortable with it – but there is more and more evidence that smell is important in social behaviours,' said Dr Roux.

The first region of the brain that processes chemosignals – the olfactory bulb – is directly connected to the limbic system, which controls the ability to identify another individual, the formation of memories, and manages emotional responses. All other senses – taste, hearing, sight and touch – are processed by other regions of the brain before being linked to the limbic system.

This may be because smell has been the most important sense for the survival of species. 'Chemical signalling is very important, even for bacteria. It's a very ancient modality, it's really key,' Dr Roux said.

PLEASURE AND PAIN

The sense of smell is linked to pleasure and depression, possibly because of its unique link to the limbic system.

Up to a third of people with a defective sense of smell experience symptoms of depression, according to a research paper published in 2014.

This may be partly because of their loss of sense of taste, and concerns about personal hygiene and social interactions. But it is also likely that olfactory loss affects the brain's functioning and in particular its emotional control, authors of the paper said.

'This might be because the olfactory system is directly linked to the limbic regions – which include the amygdala that is very important for controlling emotions,' said Dr Roux.

MICE

Dr Roux is principal investigator of sociOlfa, a project looking at how a mouse brain processes chemosignals when it encounters a new individual, and then uses them to create memories.

'Mice interact a lot by smelling the different body parts of other mice, and the nature of the smell will carry rich information (such as) the social status of the other individual,' said Dr Roux.

Animals use scent to mark – and detect – territory. In experimental conditions, if two mice fight, the one that wins will mark an area with its scent using urine. The subordinate one will also release a scent but only in one spot.

'A dominant mouse will have specific molecules to indicate they are dominant ones. And a sick animal will have signs of sickness within this odour mixture,' she said.

Female mice use scent to select a mate – usually preferring an unfamiliar male possibly because it promotes genetic diversity, says Dr Roux.

'For me it's a (form of) language. It's a way to communicate important information within a social group, important to maintain the hierarchy within the group, and it's very important for reproduction,' said Dr Roux.

Studying how mouse brains process chemosignals will help researchers understand general principles of how their brains form social memories, says Dr Roux.

And the results may be relevant in people too. Understanding how the mouse brain processes chemosignals during social interactions and when forming memories of an individual could help scientists identify what happens when these functions go wrong - for example, in mouse models of autism.

Eventually this could also help scientists understand what happens in people whose ability to recognise others is impaired – for example those with Alzheimer's – or those who have difficulties with social interactions caused by autism.



'We humans use our sense of smell more than we think. It's more unconscious, and a little bit taboo – we are not very comfortable with it – but there is more and more evidence that smell is important in social behaviours.'

~Dr Roux.

This article was originally published in:
Horizon, the EU Research and Innovation magazine.
Read the original article.

Tamara Taggart

"My son's Down syndrome does not define him"

Tamara and her husband Dave have three children: son Beckett and daughters Zoë and Poppy. They also share their home with George their Airedale Terrier, Penelope their rescue dog from Mexico, and rescue cats Broccoli and Brussel Sprout.

"Beckett is pretty amazing, all three of my children are. His extra chromosome may make doing some things hard for him, but Down syndrome is not what defines him."

~Tamara Taggart



#NOTSPECIALNEEDS

I no longer say Beckett has 'special needs'. It's important to listen to disabled people, "special needs" didn't come from the disability community, everyday I learn something new and that is a good thing. Disabled individuals get to decide the terminology they are okay with, I now know it is always okay to say 'disabled'.

SOCIAL ISOLATION

I have definitely felt isolated at different times over the years but I think a lot of it had to do with my own confidence. I was so scared when we were told Beckett had Down syndrome, I went to some 'mommy groups' when my son was very small but I always felt all the eyes on my baby and it made me feel uncomfortable. It was a tough time to navigate but once Beckett went to school I realized that he is a social butterfly, lots of friends and we have a ton of support through friends and family.

FAMILY DYNAMICS

Beckett and my daughter Zoë are only 13 months apart in age, it's always been like having twins with them! They hit all their milestones together and it was so much fun, Zoë is very protective of her brother, they have an unbreakable bond. A few years ago, Beckett left our house and walked to a very busy street, it was extremely traumatic for our family, especially Zoë. That experience changed all of us. As a family we are teaching each other all the time, my daughter Poppy is always reminding me that Beckett is a teenager now and I need to start treating him like one!

MISCONCEPTIONS

It's really annoying when I hear things like, oh 'downs kids are so happy" or "downs kids are so affectionate". First, don't say "downs kid" – UGH. Also, my child is happy and loving because that's who he is as a person, not because of his extra chromosome. My child is not an object, he is a well-rounded individual who is just like everyone else, the stereotypes society attaches to Down syndrome are exhausting and disheartening.



MY SON

Beckett is in his first year of high school, he has always loved school and the challenge of learning something new. I'm pretty sure we hold the world record for most HotWheels in one family, he loves his HotWheels!

Beckett is an incredible swimmer and dancer and he knows his way around most video games. I love watching Beckett when he is with his sisters and friends, he has an incredible sense of humour – there are a lot of laughs in our house.

CHALLENGES AND JOYS

Beckett is our first child, so he has taught my husband and I so much about parenting. My joys of parenting Beckett are the same as my joys of parenting my daughters, I love my kids so much – everything I do is for them. We're always learning in our family, the biggest thing for me right now is to guide our kids into the teenage years with respect and kindness.

My biggest challenges are how the rest of the world sees individuals with Down syndrome, there is systemic discrimination and a lot needs to change.

TO OTHER PARENTS . . .

We have been taught that having a child with a disability is nothing to celebrate, this narrative has been fueled by non-disabled people. It's not only dangerous but it is wrong, its because of this discriminatory belief that we are constantly fighting and advocating for basic human rights for individuals like my son Beckett.

Beckett is pretty amazing, all three of my children are, his extra chromosome may make doing some things hard for him but Down syndrome is not what defines him.





Born and raised in Vancouver, Tamara Taggart is a community leader, activist, veteran broadcaster, cancer survivor, mother, and former candidate in the 2019 Canadian election.

Throughout her career as a broadcaster on local television, radio and digital media, Tamara has earned her place as a trusted voice in Vancouver. For over two decades, she has volunteered her efforts on issues that relate to health care and the well-being of children and people with disabilities.

Tamara chaired BC Women's Hospital's Hope Starts Here campaign, raising $17 million for the newborn intensive care unit. She also served as chair of the BC Cancer Foundation's Inspiration Gala for five years, raising more than $16 million for cancer research and treatment in British Columbia.

2015: Tamara was awarded the **Order of BC** - the highest honour awarded by the Government of British Columbia - in recognition of her years of public service.

2016: Tamara received an Honorary Doctorate of Laws from the University of the Fraser Valley.

LISTEN TO TAMARA'S:

2014 TED Talk:
"Two Conversations that Changed My Life"
This struck a chord with medical professionals and universities around the world, by reframing the way healthcare practitioners communicate hope.

Podcast:
Telus Talks with Tamara Taggart
(wherever you listen to podcasts)

FOLLOW HER ON:
@tamarataggart

www.tamarataggart.com



A Conversation with Connor Long

Actor, Advocate, and Athlete

by Fred J. Maahs, Jr.

You've probably seen Connor Long, in a movie, or on the Red Carpet, or perhaps on a stage advocating for the rights of people with disabilities. At nearly 27 years old, he's already made a name for himself in Hollywood and in the lives of countless people with disabilities and their families. Connor is talented, smart, funny, insightful, and he happens to have Down syndrome. I first met Connor and his family when he was being honored for his work as an actor with a disability and as an advocate for people with disabilities during the Annual Convention for The Arc in 2016. The Arc is a national organization here in the United States that provides programs and services for people with intellectual and developmental disabilities. In a recent "Zoom" interview with Connor and his father, Brian, we quickly picked up where we left off several years ago – acknowledging the progress that has been made with laws and programs for people with disabilities and recognizing there is still a lot of work to be done.



Connor was born in Maryland and moved with his family to Colorado when he was 12 years old. He graduated Fairview High School, located in Boulder, with a full diploma in 2012. Connor concedes that while his primary and secondary education was good, "It was a struggle in terms of accessing the standard curriculum classes and succeed in them with appropriate support services." Connor said that it was hard work for him to keep up with a full course load and it was also hard work for his parents outside of school to make sure he could be in those regular classes.

While he liked all of his classes, his favorites were literature, geology, and algebra. Connor shared that he, "once got a D in Latin but my parents thought it was awesome that I even took Latin and that I liked it!" He continued, "My parents were very proud of my efforts as long as I did my best and that I was a good citizen-student."

Aside from his schoolwork keeping him very busy, Connor also was an avid athlete. He really enjoyed being on the





boy's swim team for four years and lettered twice! And, outside of school, he enjoyed Special Olympics swimming, soccer, basketball, bowling and bocce. He also enjoys hiking and riding his bike. Connor adds, "For the past seven years, I have ridden in the Courage Classic Tour cycling fundraiser for Down Syndrome research and clinical care programs at the Colorado Children's Hospital ."

After high school, he studied acting with the Colorado Shakespeare Festival School of Theatre and he went on to perform with the CenterStage/Tapestry Theatre Company for kids and youth of all abilities. He also performed with the Phamaly Theatre Company based in Denver, Colorado, which is formed entirely of people with disabilities across the spectrum.

Yes, Connor is an actor with a disability. He lives with Trisomy 21, also known as Down syndrome, Celiac disease, and scoliosis. Connor doesn't want to be treated any differently than anyone else – he doesn't want people to feel sorry for him and he certainly doesn't want people to underestimate him. He just wants to have the same opportunities as everyone else. And he pushes himself to always do better and to do more. While he hasn't formally gone to college, he has taken a number of non-degree and online certificate classes. Covid isn't making things easier, but Connor says, "I am enjoying a number of online classes and events, including several arts and acting classes from NYU (New York University)."
As if all of this wasn't enough to fill is day, when he is at home Connor likes to cook – mostly pasta dishes, play video games, watch cooking shows, singing, and talent shows, and he likes to watch musical theater and action/adventure movies. I need to hang out with Connor!

I asked Connor when he became an advocate for the rights of people with disabilities and what motivated him to do so. Connor replied, "I think I have always been an advocate because my parents became active in Down syndrome, disability, education and inclusion rights after I was born. When my family struggled to achieve appropriate access and services for me, we also did it for others who might face similar challenges. I was awarded the Arc's Catalyst Self-Advocate award in 2016 and I am proud to be one of the people helping to shape the future. I really enjoy being a speaker and love to keynote at conferences."

As we continued through our conversation, often filled with approving nods from Brian, Connor told me how he became interested in acting and about his roles AND awards! Connor became interested to be an actor during his youth in Maryland. Participating in church and school plays and then taking some acting classes and going to camp at the BlackRock Center for the Arts in his hometown, Germantown, Maryland. He adds that he "loves Shakespeare and hopes to act with the Colorado Shakespeare Festival Professional Company one day!" (We hope so, too!)

Connor's first role in film was when he played "Radek" in the award-winning short film, "*Menschen*", a story by Writer/Director Sarah Lotfi about the Nazi T-4 eradication program during WWII. The T-4 eradication program was an attempt by the Nazi's to kill children and adults with physical, mental, and intellectual disabilities by placing them in gas chambers disguised to look like shower stalls or by lethal injection. This was one of the worst atrocities committed by the Nazis in World War II. Connor played a young man with a disability who was hidden from harm by his mother. He says, "It was a great opportunity to combine my love of acting with the advocacy opportunity of talking about a tragic time in history." Menschen is available on several major streaming services.



Other film projects include the award-winning short film, "Learning to Drive," by Writer/Director Roderick E. Stevens. The film was screened and awarded at several disability-themed festivals around the world, including Cannes and Moscow. "I was fortunate to be invited to Moscow to speak at the US Embassy for a cultural exchange program and to receive the Breaking Down Barriers international film-festival's Best Actor Award."

Another major project was, "Weiner Dog," a social satire film that premiered at Sundance in which Connor portrayed a young married man living in the community.



More recently Connor was the host for a tongue-in-cheek series of videos on "*Disability Etiquette — How to be a good __ for a person with disabilities*," produced by Phamaly Theatre Company in Denver.

With all of these accolades and awards, Connor is recognized as a viable actor in Hollywood. And one award may just stand out above all the rest – The Emmy! Connor says receiving a regional Emmy was not on his bucket list, but he was happy to have earned one, joining his friend and colleague, Hanna Atkinson, in becoming the first known people with intellectual and developmental disabilities to win a regional Emmy award! This opportunity came from a joint initiative between Special Olympics Colorado and Denver's ABC news affiliate, KMGH/The Denver Channel/ Denver ABC7 where he reported just about weekly on the people and programs of Special Olympics Colorado (SOCO). It was a very popular show and grew to cover other events and organizations besides Special Olympics. "We produced about 32 episodes and won the Heartland Emmy for a year-in-review compilation special that covered some the of the project's most impactful stories." You can see these episodes on Connor's YouTube channel.

So, what is Connor working on these days? Well, COVID has impacted everyone but it also opened new opportunities such as qualifying for the US Down Syndrome Swimming national team where Connor hopes to earn a spot on the travel team for international competition. A number of events were canceled, so now Connor is working toward qualifying with the US Down Syndrome Swimming national team for the Down Syndrome International Swimming Organization (DSISO) world championships in Portugal in 2022. The team members across the country meet weekly on Zoom to share exercise tips and to keep in touch.

In the meantime, Connor hopes to find a flexible restaurant job once it is safer post-Covid. He is very interested to attend culinary school and continue studying acting. And, once the weather is warmer, you will find Connor riding his bike and doing physical therapy using telehealth technology. He's currently participating in a remote exercise research project through the University of Nevada Las Vegas' (UNLV) Physical Therapy Department. The program will help improve opportunities for adults with Down syndrome to stay active and healthy by participating in intensive workouts three times a week while being monitored for heart rates, respiration, etc. He also has an essay being published this year in the academic book, "At the Intersection of Disability and Drama: A Critical Anthology of New Plays." His essay is, "A Performer's Monologue" and he will be staging and filming a live performance of the essay with the goal of submitting it to film festivals.

Connor and his father strongly believe that actors with disabilities should be cast in roles that call for a person with a disability, not cast by people who only portray people with disabilities. And they also feel that people with disabilities should be cast into roles where "disability" is irrelevant to the story – so, disability is normalized and not "the story." Both Connor and Brian acknowledge that Jay Ruderman and the RudermanFoundation.org, as well as Respectability.org have made great progress on this front.

Connor has played many different types of characters and someday he hopes to play a Power Ranger! He also hopes that writers and casting agents will be more determined to place people with disabilities in projects so that what is seen in the media better reflects the people who live in our communities, including people with disabilities.

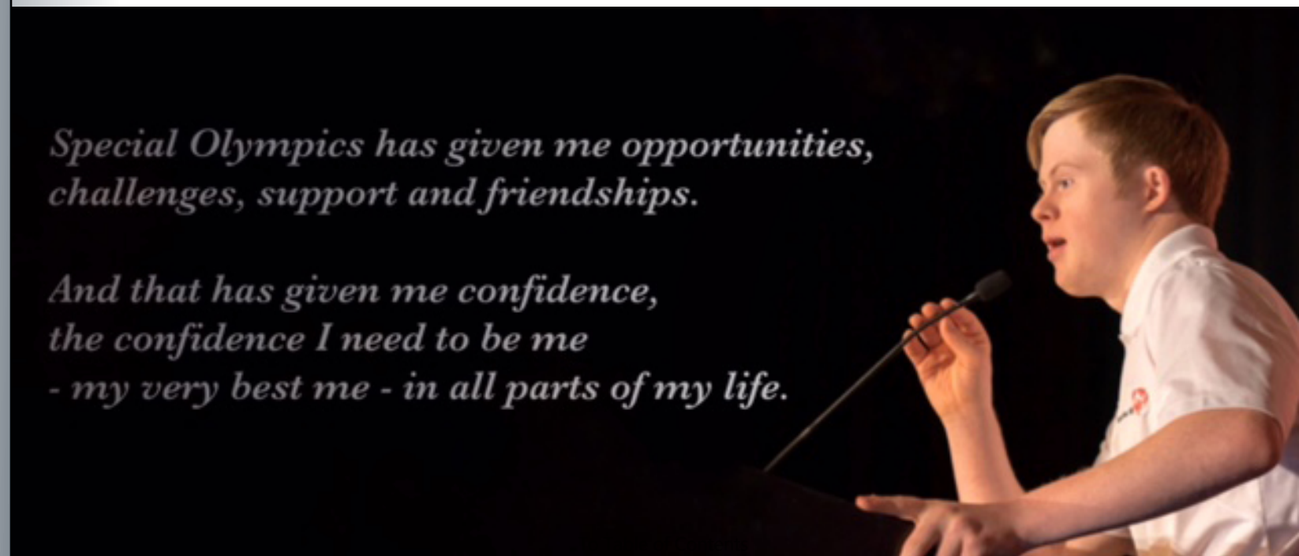
Having a child with a disability presents challenges and opportunities to parents around the world. For Brian, it has given him the opportunity to advocate not only on behalf of Connor, but also on behalf of other parents of children who have disabilities and for the disability community as well. Brian believes that people with disabilities deserve equal opportunities like everyone else and that, "Citizens can make sure they elect public officials who are humble and compassionate for people of all abilities. Government needs to seek out and listen to the lived experiences of real people and not just to politicians and special-interest groups with non-supportive agendas." We couldn't agree more.

FUN FACT ABOUT CONNOR: Connor thinks he has British ancestors because he can speak with a "good British accent." The truth is that Connor does have Irish, French, and British origins and is good with many accents after studying Spanish and Latin in school and listening to German and Dutch on Duolingo plus watching the Harry Potter and Lord of the Rings collections!

And finally, Connor concluded our conversation by saying, **"I am here because someone believed in me, in my humanity, my potential, my abilities, and my right not only to exist, but to flourish…as me!"**

I enjoyed my entire conversation with Connor and Brian. They are father and son, actor and manager, advocates, and friends. And we are fortunate to have them on the frontlines of standing up for the rights of people with disabilities everywhere. Thank you, Connor and Brian! We cannot wait to see what the future has in store for the both of you. ~*Fred Maahs, Jr.*

For more about Connor
YouTube
IMDb



All the right ingredients to be a **LEADER**

by: Fred J. Maahs, Jr.

I spoke with **Collette Divitto**, owner of *Collettey's Cookies*, and her mother, Rosemary, recently for a candid discussion about Collette, her bakery, and the relationship between them as business-owner and manager/advisor. It was an interesting, inspiring and even fun conversation. The pair frequently answered each other's questions, teased each other, and always kept it real. I knew their relationship was good and it was close, even though Collette has "fired" her mother not once, but six times! They laughed about that one.

Of course, no interview would be complete without sampling the actual product. So I went online to Colletteys.com and easily placed my order, two dozen chocolate chip cookies – without cinnamon. *(More on that later.)*

A couple of days later, a well-packaged, beautifully-adorned bounty of cookies arrived via UPS (free shipping by the way). I had a great dinner that night but the cookies were calling me. After dinner, I treated myself to two of the most delicious, fresh, chocolate chip cookies I have ever tasted. A few days later, one dozen is gone (yes, I did share with someone) and one dozen is left. Oh, and they can be frozen if you can't finish all of them. But why wouldn't you finish all of them? Honestly, once you have eaten these cookies there are no excuses for "leftovers".



Fred J. Maahs, Jr.

Collette is a bright, caring, 30 year-old woman with a true sense of who she is and where she wants to go in life. She also has Down syndrome, but do not have pity for her. It hasn't stopped her from many achievements nor would she want your pity anyway. She grew up in Ridgefield, Connecticut and began her love of baking at 4 years of age but really didn't begin serious baking until she was a few years older. After taking some baking classes in high-school, she came up with a recipe for a chocolate chip cookie with cinnamon, and it was a hit! That cookie is now referred to as "*The Amazing Cookie*" and is the featured cookie on Collettey's web site.

After high-school she finished a three year LIFE program at Clemson University in just two years. It was then she decided to move to Boston because she was "sure to find work there." But, as is the case with so many people with disabilities, the unemployment rate is more than twice that of people who do not have a disability, even though qualified and able to work, Collette was rejected by many employers. She wasn't about to let this defeat her and decided that she would turn her passion for baking into a business and founded "Collettey's Cookies" and her first orders were sold by a local grocery store. And, one would argue, her big break came in 2016 after a local news station did a piece on her. She hasn't looked back since!

But, having a business that sold product wasn't enough for Collette. It's always been important for her to give back to the community and to make sure that she employed other people with disabilities. Today, she has 17 employees, about half of whom have some type of disability. Each day, her staff makes the dough, bakes, and packages about 140 fresh orders of cookies. Collettey's also makes fresh, organic dog biscuits. That's right, dog biscuits. Tasty enough for a human, but made special for canines. And, because Collette believes being employed is an opportunity that applies to everyone, she has recently hired a person who was once homeless. Collette also started a Foundation, Collettey's Leadership. Because she feel so strongly about entrepreneurship, she felt it was necessary to help others so she travels around the country providing workshops, speeches, training, as well as leadership and empowerment sessions to people with and without disabilities. Her website has all the information you may need about her leadership programs.

As you can imagine, Collette has traveled quite a bit during her speaking engagements, but her favorite trip of all was when she spent two weeks in San Diego to visit her sister. She said they would sit on the cliffs and watch the sunset and that it was good just spending time together.

It seems, almost obviously, that Collette's strong work ethic and drive comes from her mother. Rosemary is not only busy with her own business in construction, but took on the additional responsibility of being Collette's manager and Board Chair of Collette's Foundation. According to Rosemary, she "had to step in and help Collette when 60-80 emails a day with orders and questions were coming in from all around the world."

And, if that wasn't enough, Collette is trying to establish "franchise" opportunities for people interested to start their own Collettey's franchise and she insists she will be on-site for the first month to train staff. (Rosemary insists Collette wants to be on-site because she must have everything dome properly and to protect the brand. Hmmm. Not a bad thing!) The true premise behind offering these business opportunities is that Collette believes in empowering people with disabilities to live more independently and being employed is a major step towards that independence.

But, why stop there? Who knew there were actually more than 24 hours in a day? Well, it would seem this dynamic duo of Rosemary and Collette found them because soon Collette will appear in a reality-type show called, "Born for Business" which will feature Collette and her busy day-to-day, real-life, goings on. Filming has completed and the show will air on a major outlet soon, and Season Two begins filming soon. When does Collette and her mom find time to sleep?

Collette does confess to having some spare time and that's when she is able to spend time with friends having dinner and cocktails, going to concerts and sporting events, hiking, and skiing. Hard work, great time management skills, delivers a great product… And, we already know she has all the right ingredients to be a leader.

Our conversation was delightful and I do hope we stay in touch to check on the progress being made for business growth, but more importantly, to stay in touch with a new friend!

Thank you, Collette and Rosemary, for spending time with me and for sharing your story with our readers. And, don't forget to place your orders for fabulous cookies and more at [www.Colletteys.com.](http://www.Colletteys.com)

For more information about Collette, [click here](#).

> . . . It's always been important for [Collette] to give back to the community and to make sure that she employed other people with disabilities. Today, she has 17 employees, about half of whom have some type of disability.



To Table of Contents



Chef Seth Saheli

partially blind but creating

your next recipe

COOKING BACKGROUND

As a young child my mom cooked on a daily basis, until she eventually opened a small but very popular restaurant. At home on the Caribbean island of St. Kitts, I would sit on a high stool in the kitchen observing her every move and taking mental notes. I was eventually able to help at the restaurant when I got older my love for cooking really grew. As I entered into adulthood, although I was always cooking, I never saw it as a career. I was focused on Business Management and Marketing, my preferred career path at that time, fueled too because of my father who was a salesman and business owner.

During my adult life, I held job titles such as General Manager and Marketing Manager. I was quite comfortable but always felt something was missing - I felt incomplete, until one day I woke up with a bright idea. Why not start a business based on my love for cooking - after all, I constantly received compliments from my family and colleagues!

So, this is where it began. I created *Meaningful Mealz*, a daily lunch delivery service targeting the business/working sector who had the challenges of the dealing with the lunch time rush, tight traffic, short lunch break etc. I had experience managing restaurants and was also kitchen manager, securing a wealth of experience from fast food operations to high end fine dining but as the business progressed, I improved my skills by taking online culinary courses and even shifted from the Management field and sought experience in more culinary-based businesses. My opportunities expanded to include corporate catering, private chef concierge services, and culinary consultancy. Over the years, my skills, experience and talents directed me into now becoming a cookbook author, which I am very honoured and grateful to have accomplished.

PARTIAL BLINDNESS

Over the past few years, even today, I'm being plagued with eye challenges, from having to wear glasses to regular eye discomforts. I went through a variety of eye procedures and surgeries and it has been quite a bit of a struggle.

Late 2019, my vision was extremely bad and I was experiencing a series of eye pains. I was scheduled for laser eye surgery which would have helped my vision and my options were to either go overseas or book an appointment for have surgery done in St. Kitts as a team of

US ophthalmologist were scheduled to visit the island. My appointment was scheduled April 2020, but unknowingly, Covid-19 had other plans. By that date, our country was shut down, all borders were closed, no flights were coming in or out, and no travelling to anywhere allowed. I therefore lost the opportunity to have my eye surgery done and because of this, about a month later, I lost all vision in my right eye.

It was a tremendously heart wrenching time for me, so devastating that I worried and stressed to such an extend that I had to be hospitalized for three weeks. It was by far the lowest point in my life, and I lost all hope. Through all of my anguish, I kept my faith but I would lie on the hospital bed and ask "Why me? What did I do to deserve this? I'm not a bad person, I take care of my family, my responsibilities, I care for and help so many people, I love God, so why did this have to happen to me?."

I must admit, I lost hope, but with the love, care and encouragement of my mom and family, I was able to see a glimmer of light and started to suppress my negative thoughts. With continuous prayer and positive thoughts I began to accept my fate.

When I got out of the hospital, I had to make drastic changes in my life based on my now disability. It wasn't life as usual for me anymore. I had to resort to living with family as being blind in one eye and the other eye not being 100% functional meant that I would need assistance. It also meant that I wouldn't be able to work as efficiently and effectively at the level that I and my clients were used to. Reality of life soon became my main focus.

I recall the doctors' visits at the hospital always created mixed feelings for me. I was told yes, I am recovering physically overall, but I would never be able to see out of my right eye again. Every time I heard this, it got me down but I started thinking: "I wasn't dead, I was only slowed down. I had life, and with life there are still endless possibilities." Then it dawned on me - I should finish my cookbook. Alas! Here was something positive and meaningful I can focus on while I was lying on my hospital bed.

From the many private chef jobs I did for visitors to my island, I had already started putting recipes together in my mind with the thought that maybe one day I'd have my own book. Before my partial blindness, I was encouraged by a good friend in Canada to look into publishing a cookbook to capture all of the wonderful dishes I would have created during my career as a chef. So, it was then clear to me what I wanted to do next.

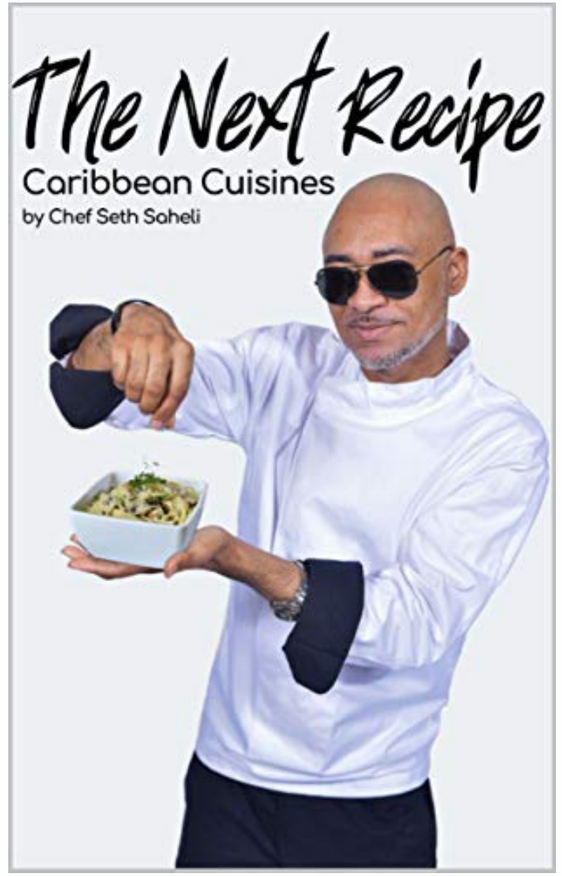
After making all the necessary decisions and adjustments to my life, I was determined to continue with my book and gave myself a deadline to get it completed by early 2021. I put my thoughts together and with the assistance of my loving sister, Amal, who lives on the island of Antigua, I was able to start my book. I would call her daily, give her the recipes, procedures, measurements etc. and she would type them out for me.

I was challenged by my lack of vision, the daily eye pain and rigors of my new life, but it only motivated me more. With the continued assistance of family and loved ones, I was able to complete my book. It was published and *available on Amazon* by November 2020.

If you're going through a similar situation, once you have life and you can acquire a positive outlook, you can still accomplish your goals and your dreams.

With my disability and its constant challenges, being able to produce and publish my cookbook has given me great satisfaction, because this is one way that I can inspire and motivate others. I want to show others out there who are going through the same or similar situation whether health-related or other, that once you have life and acquire a positive outlook, you can still accomplish your goals and dreams. You may help someone to achieve happiness by being their inspiration.

I love being a private chef . . . I love creating memories, the reactions from the clients, being able to bring smiles and amazement to their faces and of course pleasure to their pallets! Many times, we become lifelong friends and continue to keep in touch. This is very rewarding and I am truly grateful for that.



Chef Seth will be available for private chef services when travel resumes.
Visitors to St. Kitts and Nevis can contact him by email: chefsethsaheli@gmail.com

Website: www.chefsethsaheli.com

Caribbean Recipe



Caribbean Creole Lobster

By Chef Seth Saheli

INGREDIENTS

4 Large Lobster tails (shell removed and sliced into chunks)

1 cup Master seasoning blend

2 large tomatoes diced

1 small ginger (peeled and thinly sliced)

2 tbsp unsalted butter

4 cloves garlic (peeled and thinly sliced)

1 tbsp tomato paste

Salt and pepper to taste

2 tsp Creole seasoning

2 lemons

1 bunch Fresh parsley

1/4 tsp olive oil

1 cup water

PREPARATION

In food processor add parsley, juice of 1 lemon, oil, master seasoning blend, tomatoes, garlic and ginger, pulse until slightly chunky.

In medium sauce pan over medium heat, add mixture along with tomato paste, creole seasoning and water.

Bring to boil then turn heat down and let simmer for 10 to 12 minutes. Add salt and pepper to taste.

Add lobster meat and let cook for 10 minutes.

Use large spoon to stir gently and to apply creole sauce over lobster.

Cover and let cook for another 10 minutes until lobster is tender.

Remove from heat and garnish with lemon wedges, serve with your favourite side dishes, enjoy.

To Table of Contents



Raising Nathan is the heartfelt story of the struggle faced by Jamaican parents on discovering that their son would be born with a major disability - and a prognosis that he will not survive childhood. Written by Nathan's mom in a conversational, down-to-earth style, it recounts the enormous challenge of coming to terms with his special needs, and details the journey that has bound his family together - growing their faith and inspiring courage.

Available on Amazon

Parent Advocate

Christine E. Staple Ebanks

The 2nd in a series of articles about parent advocacy and the Nathan Ebanks Foundation [CLICK HERE to read part one]





Raising Nathan

My son, Nathan, is the last of my four children. If I were to think of one word to describe him, it would be 'impish' . . .

Public misconceptions about children with special needs poses such an important conversation, that in my first book – *Raising Nathan: Every Life has a Story*, I dedicated an entire chapter to the topic. I have found for myself and countless other parents I have spoken with over the years, that these misconceptions play out negatively for the children and messes with the family's acceptance of the child as a person. Two of the most significant ones are:

(1). A child's disability happens because of something the parent has done wrong in the past that God is punishing them for.

(2). Children with disabilities aren't worth the investment. All they need is to be fed, clothed, and kept at home. They are not viable human beings. I remember having a specialist in Jamaica tell us "Not to bother with this one as he will never, ever…", there was also the owner of a company which sells rehabilitation equipment who told me that "I am to stop giving parents false hope into thinking their child with disability can become more".

I cannot stress enough how wrong these are. Much of my speaking work has been about shifting mindsets around such thinking and helping parents to see beyond their disability and learn to see the gift that is their child.

In my book, *How to Cope: Parenting a Child with Special Needs* which was released earlier in 2020, I invited my husband and older children to share their experience of having a son and brother with disabilities. In carrying out their interviews, it was the first time



that we were ever having this discussion, though it had felt like Nathan's disability was all we talked about over the years. I was moved by the depth of the feelings of each member of my family following the diagnosis and beyond. At the time of Nathan's birth, his siblings were very young – 8, 6 and 4. Yet the impact was profound, and what was worst, I was so wrapped up in my own grief that I didn't realize how much they were hurting.

I am grateful that before Nathan was born, we were already a close-knitted family. Somehow, we were able to transcend the challenges and grow even more close, so that Nathan has an impenetrable wall of support surrounding him. Today, his siblings are 24, 22 and 20, and I have to jokingly remind them that Nathan has only one mom, because they all act like they are his parents (it brings a smile to my face every time I think about this).

Nathan is a much like a typical child in many ways. He is brilliant, vivacious, and social young man. Though he has gone through more health issues than most and lives with a very debilitating disability (cerebral palsy), he is joyful and wears a "million Dollar Smile!". He is extremely passionate about life, love to go on trips (we were once lost for 14 hours in Florida and while the rest of us panicked, it was merely an adventure for him). He likes school of the social activities, hate schoolwork and his favorite pastime is watch TV. We have always tried to give him as many opportunities as his siblings, so he has his own special brand of swimming (one leg beating the water at a time), athletics -he participated in the wheelchair at his old school in Jamaica (was the only person who went backwards in his chair) and tries his had at floor ball (football for children with disabilities). He was in the dance club at his old school in Jamaica and dabbled in art where he entered and was placed 10th in a National Art Competition for children with special needs in Jamaica (2017). However, due to the limited availability of rehabilitation therapies (Occupational, Speech and Physical) in Jamaica, and the low availability of equipment such as adaptive wheelchairs, augmented communication systems, at 16 years old, Nathan is not able to walk, feed himself or brush his teeth. He carries low weight and is adaptive skills are well below is capability.

Since mid-2020, we are living in the United States. Nathan has just started school and we are excited to see the possibilities when he is given the supports, he needs.

I have often shared that it was never Nathan's disability which challenged me the most. It was the not knowing. Not having the information earlier on that would have helped me to be more intentional in the things I did with him. It was the fact that the view of my son was obscured by the "specialness of his needs". It overwhelmed me for a while --- 2 ½ years to be exact. Time that I should have spent bonding with my son, was spent cowering in crippling fear that he would die. I didn't know at that time that cerebral was not a "death sentence." I had no one to turn to.

Each day I would look at my child and because I didn't understand what the disability meant or what I was seeing him do, it made me feel for a while that he was "broken." This eclipsed the joy of parenting a beautiful child, and I feel like I missed out on those early years. I guess that is partly why I am so passionate to talk parents, especially when they have just gotten the diagnosis. I wished someone had talked to me then. Since the day I learned to see him, to really see Nathan, he has brought me, our family and everyone who meet him so much joy. When he laughs, it is so infectious, that everyone laughs with him, even if the "joke" was all that funny (smile). Today as I look back, the way I see it, 16 years ago when my son's Nathan was first diagnosed with a disability – cerebral palsy (CP), I thought my life was over. I thought that I would spend the rest of my days locked away caring for a "disabled" child. I had never felt such pain, despondence, and hopelessness as I did then. It felt like wherever I looked all I could see was despair. I felt powerless. Back then, there was no one I could turn to help me make sense of this diagnosis. I didn't know how to pick up the pieces. Yet, somehow, my faith in God, my family and close friends and my village community of supporters saw me through.

Today, looking back I can see clearly how what came to my family as "tragedy" became a beacon of hope for so many children, families, and people with disabilities. My son's life has made a difference for thousands of children with disabilities and their families in Jamaica. He has inspired a movement to increase the participation, inclusion, and empowerment of people with disabilities in Jamaica and other countries that I have been to speak. He has taught me that every life matters! I am thankful for the gift of my son Nathan.

I have often shared that it was never Nathan's disability which challenged me the most. It was the not knowing.





Nathan Ebanks FOUNDATION

Since 2007, the Nathan Ebanks Foundation has:

1. Provided direct intervention services – in speech, occupational and physical therapy and screening services to 2000+ children
2. Held over 8 annual disability and special needs conferences impacting 3,000+ teachers, policymakers, parents
3. Created and delivered key Train-the-Trainer Inclusive Education Training Institute to the Ministry of Education. Impacted more than 2000 teachers.
4. Hosted 4 Special Needs Resource Fairs connecting more than 8,000 persons to services
5. Published 2 Children with Special Needs Guide to Resources Handbooks distributed free to 3000 in Print, Digital and Audio formats
6. Contributed to policy changes by serving on 7+ high-level national boards and committees including the National Disability Advisory Board and the education and disability sector groups
7. Hosted the inaugural Special Child, Special Needs Virtual Parenting Summit: 1200 + attended/viewed the recording from 23 Countries

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To Table of Contents



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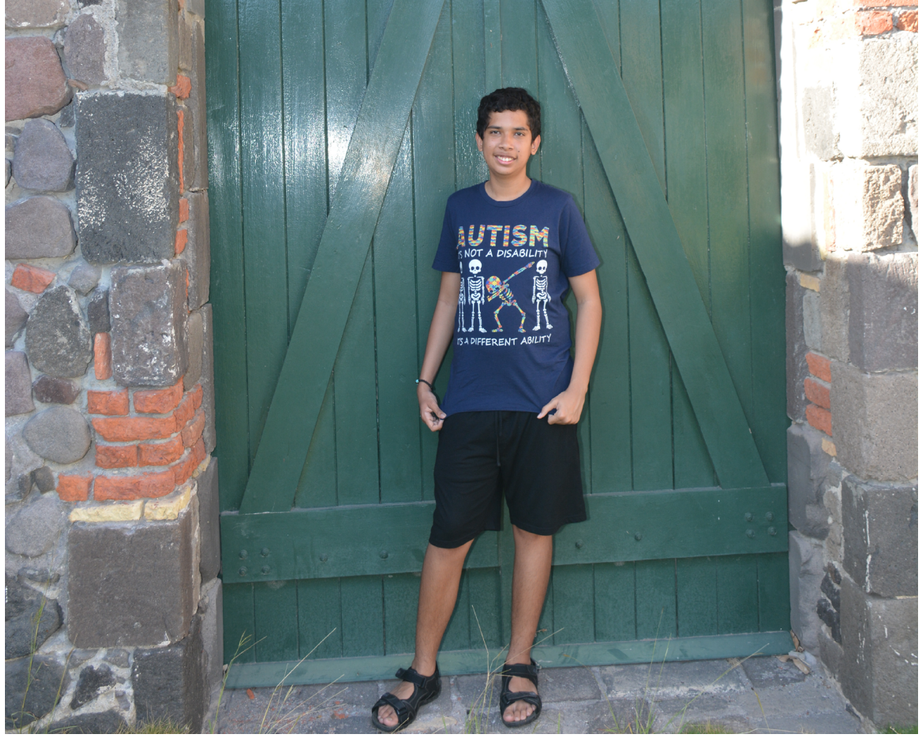
To Table of Contents



Maya Pandt lives with her son, Jurgen, on the Dutch Caribbean island of St. Eustatius. Here, as in so many other places, disability is a taboo subject. People do not like talking about it, many do not understand it and it makes others feel uncomfortable. Jurgen is her only child and he is autistic.

On this small island of about 3,500 people with limited resources in that field, it was at first very difficult to get a diagnosis. Jurgen had stopped speaking at the age of 13 months and could not stand loud noises. She could not comprehend his melt-downs and no one was able to offer solutions. While reading an article one day about a child who displayed similar behaviour, the thought occurred to her that Jurgen may be autistic. She found a mock-test online, and the results indicated he may indeed be autistic but that was still just a suspicion. An Expertise Center was eventually opened on the island in 2011. Jurgen was tested and at 7 years old, formally diagnosed with PDD NOS which falls under the autism umbrella. Equipped with that knowledge,



Maya was then able to seek the help he needed. Jurgen is now 14, attends mainstream school, is fully vocal, loves to draw, is intrigued with the universe, the stars and the night sky and absolutely loves to play video games with his friends.

Misconceptions about autism pervade many societies and because it is not understood, families live with the stress that lack of knowledge and sensitivity brings. Jurgen's meltdowns were usually at home but he was bullied at daycare and first 2 years of elementary school, the other children would hurt him and being non-verbal at that time, he could not tell his parents what happened. The society tries to see a look and not understand it has nothing to do with looks, but neurological "they say he doesn't look autistic," Maya expressed with dismay, but she knows her son is full of potential.

Thankfully, teachers on the island are now more aware, and some are being trained to work with special needs children; other kids on the island have since then being diagnosed with autism and, like Jurgen, attend mainstream schools. Jurgen has a high IQ, is able to learn at his own pace and some of the previous frustrations Maya felt have dissipated. But there still remains a lot of work to be done on St. Eustatius.

Maya believes that even now, parents of children with special needs are not as vocal as they should be. She wants people in the community to understand that because a child sees, hears and sometimes behave differently to others, they are still intelligent and have a lot to offer to society. Maya's need for community awareness of autism has led to the creation of the JTL Autism Foundation (named after her son, Jurgen Timothy Leon) in March 2021. The Foundation will provide much-needed support to parents and children on the spectrum. They will conduct workshops, partner with nutritionists, speech, occupational and motor skills therapists and other professionals to educate, diagnose and treat people with autism on St. Eustatius.



Maya and the Foundation's board members hope acceptance and non-judgmental attitudes towards people with disabilities will result from the programs they will offer. Maya says very often, she is moved to be transparent at the beginning of an interaction between Jurgen and others. She will let them know at the onset that her son has autism. He also does the same, at times. If not, people's attitude towards him may not be favourable. Someone may say something to him and expect an immediate response which they many not receive, as he has to first process the question or comment before attempting an answer. They may then interpret his reaction or lack thereof as being rude or otherwise. Jurgen once asked her,

"Mom, will people like me more if I was not autistic?"

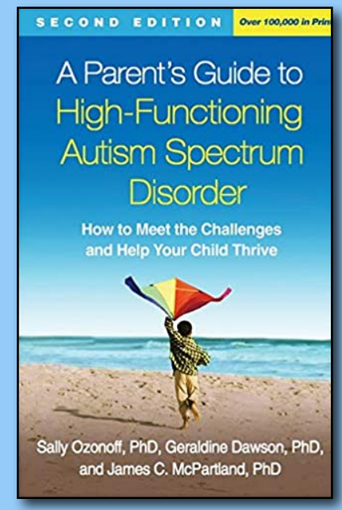
This question broke her heart!

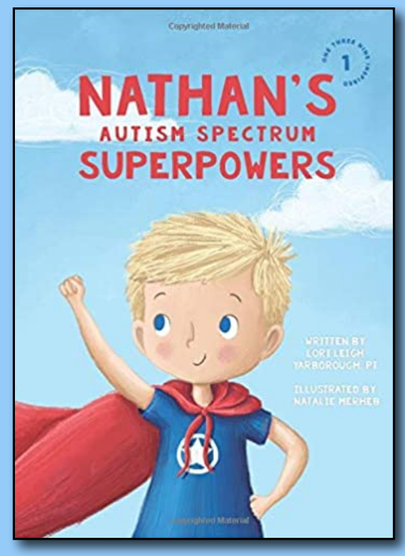
Maya's advice to parents is to embrace their child, shower them with love and nurture them to become the best that they can be, regardless of their abilities. Jurgen brings immense joy into the home and he has an incredible sense of humour which helps them get through tough moments. He's always joking around with his mom and they maintain a great relationship. She encourages him to talk to her about anything so he comes to her with his every thought. She is very patient and has implemented structure and a daily routine into the household which helps him to get through his day. Maya is a divorcee and raising Jurgen as a single parent is challenging, but he lights up a room and infuses it with his genuine love of the simple things in life. What others may interpret as mental delay is to her, great intelligence, as she understands that her son sees things from a different perspective, after all, he was the class valedictorian in his elementary school and did a marvelous job!

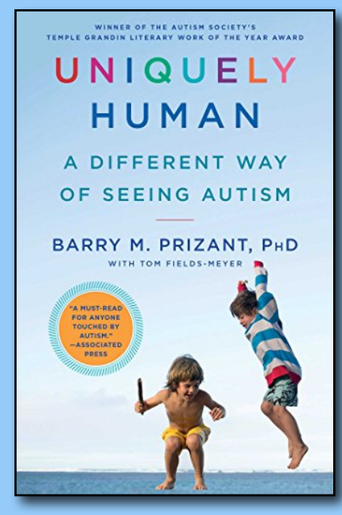
Maya and the Board Members of the JTL Autism Foundation are committed to using it as a platform to educate, sensitize and change perceptions, ultimately creating a more inclusive and accepting St. Eustatius for people with disabilities.

What others may interpret as mental delay is, to Maya, great intelligence, as she understands that her son sees things from a different perspective . . .

To Table of Contents







TRAVEL-FOR-ALL'S

TIPS for travelling with an autistic child

It will come as no surprise that traveling with children with Autism Spectrum Disorder (ASD) can be challenging in the same way that any kind of social outings can be difficult. But there are some tips that can help you.

(1) If your child is already in a program with us, let us know about your travel plans. Our programs are individually tailored to each child. If you have some special travel plans coming up, we can work with your child to help him or her prepare. We can also give you, the parent, activities, and exercises to do at home to help the child get ready for the trip.

(2) Role play at home. If possible, do some role-playing at home to show the child what he or she can expect in a plane or train or long car ride. Talk about what the child will see and hear and experience to defuse any anxiety.

(3) Take something soothing. Try to bring something for the child that is soothing, whatever that is. A stuffed animal or blanket or a toy. Have something available to quiet the over-stimulated child.

(4) Bring earplugs or headphones for the sound-sensitive child. If your child is very sensitive to noise, then an airport or a crowded ferry terminal can be a scary place. Earplugs or headphones are an easy way to dull ambient noise.

(5) Prepare for meals in advance. If your child is fussy about food, then take food with you rather than rely on what you may or may not find during the trip. Any child is irritable if the child is hungry or thirsty, so try to take that worry out of the equation.

(6) Increase safety precautions. Wandering off or "elopement" is a problem for about half of the children with ASD, and this problem is magnified when the child is no longer familiar with the surroundings. So, if you travel, have the child wear a medic alert bracelet with his or her name and contact information and/or have that information affixed inside their clothing in case the child is separated from you.

> *"Appeal to your child's special interests. Consider bringing along something new that you know your child will like."*

(7) Plan trips to appeal to the child. While this is not always possible, if it is possible, then the trip may be happier for everyone. If the child likes water, take him or her to the beach. If the child likes airplanes or rockets, take the child to an air or space museum. This sounds so simple, but not all parents seriously consider what best suits the child on a trip or a vacation.

(8) Keep daily routines even when away. Everyone young and old benefits from a daily routine. And this is even more important for an autistic child. Whenever possible try to follow your at-home routines even when you are away. This predictability reduces stress and anxiety and helps the child feel more in control.

(9) Arrange things in advance. Figure out your schedule and hotel stop in advance and ask for help if you need it. Airports and hotels have guest services that can lend a hand.

If you are flying, many major airports offer support for preparing a child with Autism. Click here for Vancouver International Airport's Autism Travel Resources

Travel-for-All
Global Accessible Travel Specialists

To Table of Contents



DR. JENNIFER CAMULLI
Autism, Inclusion, Accessibility and Expo 2020 Dubai

Dr Jennifer Camulli has over 30 years' experience in working with and advocating for people with disabilities. Her previous roles include Certified Accessibility Consultant, Certified Educational Therapist and Head of Inclusion.

She is currently leading the efforts to place accessibility at the heart of planning for Expo 2020 Dubai, the first World Expo to take place in the Middle East, Africa and South Asia region. Running from 1 October, 2021 until 31 March, 2022, Expo 2020 is a global gathering dedicated to bringing together people, communities and nations to build bridges, inspire action and deliver real-life solutions to real-life challenges.

Visit www.expo2020dubai.com to find out more.

April is World Autism Awareness Month, which is dedicated to increasing awareness about Autism Spectrum Disorder. Is it possible for someone to be autistic and not know it?

Yes, absolutely. Many people do not know they have autism until they receive an official diagnosis. And even then, if they are very young, they may not know or fully understand what autism means until they are older, or if there is moderate to severe intellectual impairment, they may never really understand it. It's also becoming increasingly common for adults to come forward for self-referral if they suspect that some of the social and communication challenges they have had since a young age can possibly be accounted for with a diagnosis of autism.

How effective is inclusive education?

Like any process or service, it is only as good as the people delivering it. Globally, there are different approaches to inclusive education, often because of varying levels of awareness, different cultural perspectives, and both the ability and willingness to adapt teaching methods and curriculum content.

What are some of the key variables for the successful implementation of inclusive education?

To begin with, if inclusive education isn't mandated by the relevant authorities, schools may opt to either not offer it at all or be selective in their admission offers. Equally, if a school's leadership team isn't fully committed to the principles of inclusive education, its implementation and practice will also suffer.

It's also incredibly important to ensure that each and every student has the opportunity to experience success at school, no matter what that looks like. Everyone deserves the right to achieve – it's tied so intrinsically to the concept of dignity and self-worth. For example, allowances should be made for students to advance with their peers and participate in graduation ceremonies. Even if a student hasn't met the criteria to officially graduate, they can still be presented with a certificate of achievement and celebrate with their classmates. The need to belong is strong, and schools need to enable this.

What are some of the critical steps for building an inclusive workplace?

Successful inclusive workplaces are those that foster a collaborative work environment, where everyone has a voice. Consultation with the disabled person on what accommodations s/he may need in the workplace, including the option to work from home, facilitates empowerment and trust. Employees should also be provided with regular training on engaging with colleagues with disabilities and it's a particularly powerful statement when an organisation has a dedicated Inclusion Team, or a group of Inclusion Champions. Consideration should also be given to providing accessible communication for physical and virtual meetings where required, such as live captioning.

What is the theme of Expo 2020 and when/where in Dubai will it be held?

At Expo 2020 Dubai, you'll experience the world in one place – a global gathering dedicated to bringing together people, communities and nations to build bridges, inspire action and deliver real-life solutions to real-life problems. Expo's theme of 'Connecting Minds, Creating the Future' is underpinned by three subthemes – Opportunity, Mobility and Sustainability – that we believe are the three key drivers of human progress and prosperity, and are aligned with the Sustainable Development Goals.

Expo 2020 will take place in Dubai between 1 October, 2021 and 31 March, 2022, on an incredible 4.38 sq km site in Dubai South. Dubai is easily reached by sea, air or land, and Expo will be well-served by public transport, including the world-class Dubai Metro and dedicated Expo Rider bus service.

How easy will it be for people of determination to navigate their way around the Expo? What are some of the accessibility services and features that will be in place for them?

People of determination have been a key priority in our planning from the very beginning and we've made sure to include a number of measures to enable them to navigate the site easily and safely, to enjoy an incredible visitor experience.

For example, we've installed 14 tactile maps around the site which will provide raised and embossed images of the area nearest to them as well as audio output and braille. And we have also developed our PODium app, in collaboration with SAP, an Official Premier Partner of Expo 2020. The app provides 3-D visual mapping, audio navigation and haptic feedback to assist visitors with these needs. Our Thematic Pavilions also have tactile maps to assist visitors in understanding the environment around them. There are 15 Information Centres across the site and an additional seven Information Kiosks that can provide important information to all our visitors.

In addition to this, we've also created four Quiet Rooms on

To Table of Contents

site, with innovative sensory equipment and relaxation areas for any visitor experiencing sensory overload or anxiety, and we will offer ear defenders and sunglasses for visitors with sensory sensitivities. We have developed social stories that will be downloadable from the Expo 2020 website that provide sensory information on the different Expo visitor experiences and will provide 'Sunflower Lanyards' on request for those who wish to discretely signal that they have a hidden disability. We are proud to say that these efforts have been recognised by the International Board of Sensory Accessibility, and as we get ready to mark World Autism Awareness Day on 1 April, Expo 2020 is set to be officially named as a Sensory Accessible Event – a first for a World Expo and a first in the entire Middle East.

For our hearing- or vision-impaired visitors specifically, we have installed hearing induction loops at key locations across the site and created service dog relief areas. There will be 3-D tactile models of our flagship architecture, and scannable codes for self-guided experiences narrated through sign language, audio description and written captions.

In addition, tickets will be available free of charge for all people of determination and at half price for their companion.

You bring "a holistic approach to accessibility by merging four domains: ecogenic domain (built environment), technogenic domain (digital environment), sociogenic domain (social environment) and the sensorigenic domain (sensory environment) to ensure a fully inclusive experience." Can you tell us a bit about the relationship between the four domains and how they are collectively incorporated into the Expo setting to make it more accessible?

Typically, accessibility is approached from either a built-environment perspective based on standards of Universal Design, or a digital environment perspective, for example accessible websites that comply with the Web Content Accessibility Guidelines. These are often done in isolation of one another and focused on standards and codes only. This approach risks missing out on what visitors really need. The holistic approach I refer to merges four domains to achieve a more rounded and inclusive experience.

At Expo 2020, it began with community engagement, which was key to understanding the various journeys that people of determination may take to visit Expo 2020 Dubai.

We held accessibility forums that allowed us to hear directly from stakeholders

Our approach is based on the principle of 'nothing for them without them'.

In taking a more holistic approach, we considered the visitor journey in its entirety, all the way from planning their visit (website accessibility) to arriving in Dubai (accessible services at the airport) and arriving at Expo 2020 via accessible means of transport. This means looking at the social environment (inclusive hiring practices, staff training etc), the built environment (the physical site), the digital environment (our website, apps and digital interfaces) and the sensory environment (quiet rooms, social stories etc) in parallel and with equal weighting.

Dubai published the Dubai Universal Design Codes in 2017 and the government has worked quickly to ensure its implementation – this has included retrofitting government buildings and adapting digital platforms and public spaces.

For our many visitors, all major hotels offer accessible suites, the Dubai Metro system is fully accessible, there are accessible taxis, and many restaurants will offer provisions if a visitor advises them in advance. People of determination, including those who are tourists, can avail free parking passes from the Roads and Transport Authority and discounts and privileges from the Community Development Authority's Sanad card. Entrance fees to a range of visitor attractions are waived for people of determination, including Expo 2020 Dubai. And Emirates Airline boasts dozens of inflight movies with audio description and captions, making the journey to Dubai more accessible.

We have to remember that accessibility is a journey not a destination – it takes time and budgeting to implement for business owners, venues, and spaces. Most tourist venues have provisions in place, while others have established a plan for retrofitting over a time span. Historical areas are more difficult because the integrity of a building has to be maintained and a strategic plan needs to be developed in consultation with accessibility professionals. Nonetheless, in three years, huge strides have been taken.

When travel and tourism begins its "reboot" post-COVID, would you say that Dubai is ready for the potential influx of travellers with disabilities who may be visiting, especially after the Expo is over?

Dubai was one of the first cities to reopen to the world last summer, and across the UAE, the authorities have taken clear and decisive action to protect the safety and well-being of all citizens, residents and visitors. For people of determination specifically, the 'Rest Assured' initiative was introduced to provide specialised support for the challenges raised by the pandemic.

The health and safety of everyone at Expo 2020, including our workforce, participants and visitors, has always been our first priority in our planning and operations, and the global health challenges of the past 12 months have put this into even sharper focus. We continue to work closely with the relevant local and international authorities to implement and uphold best practice, including capacity control, social distancing, thermal scanners, sanitisation procedures and the vaccination of our workforce.

When we open our doors to the world on 1 October, we will be ready to offer an unforgettable, once-in-a-lifetime experience for every visitor, from every walk of life, from every country. It is our ambition that our industry-leading efforts to provide a fully inclusive event will be an important part of the Expo's long-term legacy, both regionally and internationally.

"[Expo 2020 Dubai] . . . People of determination have been a key priority in our planning from the very beginning and we've made sure to include a number of measures to enable them to navigate the site easily and safely, to enjoy an incredible visitor experience."

~ Dr. Jennifer Camulli

Times. They are a-changing.

2021 – a Pivotal Year for Accessible Restrooms in England

By Helen Evans of Aveso

The UK's Changing Places campaign has come a long way since it was launched in 2006. Significant successes have been achieved in 2021 after years of hard work, including the introduction of new legislation requiring venues to include Changing Places Toilets (Restrooms) and the announcement of £30m in funding that will be allocated through local councils to encourage more Changing Places to be installed across England.

There are 13.9 million disabled people in the UK. A proportion of those - people with profound and multiple learning disabilities, as well as people with other physical disabilities - often need equipment, such as a hoist and changing table, and space to allow them to use restroom facilities safely and comfortably. With a lack of Changing Places, many people (including families) are effectively excluded from being able to do all of the things that they want to do.

The Changing Places Consortium (a group of like-minded charities and organisations) launched its campaign in 2006 on behalf of the over 250,000 people across the UK who cannot use standard accessible restrooms. This includes people with muscle-wasting conditions, profound and multiple learning disabilities, motor neurone disease, multiple sclerosis, cerebral palsy, as well as older people. Since then the Consortium and many hard-working individual campaigners have pressed organisations and Government with the goal of making the installation of these facilities a priority.

The Consortium created a set of Changing Places specification requirements, ensuring that all facilities installed are built to the same standard and maximise their accessibility. Changing Places restrooms provide more space (12sqm2) than a standard disabled restroom in order to accommodate the disabled person and two carers. They are also required to include a height adjustable adult-sized changing bench and a ceiling track hoist. Other specialist equipment such as height adjustable washbasins, peninsular toilets, a privacy screen and grab rails are also included.



A Changing Places toilet at the Friary Shopping Mall, Guildford

One of the major successes of this year has been the introduction by the UK Government of new legislation requiring Changing Places to be designed and built into new and re-developed public buildings over a certain size. The legislation became law for England in January 2021, following the legislation already set in Scotland. The Government estimates that Changing Places Toilets will be added to a minimum of 150 new buildings per year in England as a result. Shopping malls, supermarkets, cinemas, stadia and arts venues are just some of the buildings that are now required to include at least one Changing Places Toilet in any new build or major refurbishment.

As the legislation stands, there is no legal requirement to retrospectively fit existing buildings. However, the newly announced £30m of funding for Changing Places will enable local councils to decide where in their area, including in existing public buildings, Changing Places restrooms are most needed. This will help expand the network of facilities across England.

While announcing the provision of the £30m of funding, Regional Growth Minister Luke Hall MP said:

'For too long, the lack of suitable toilet facilities has meant disabled people have faced major difficulties when they

To Table of Contents

shop, go out, or travel and this should not be the case. That's why the provision of Changing Places toilets is so important for people who cannot use standard accessible toilets.'

2021 is certainly a pivotal year, and a great deal has been achieved, but the job is by no means done. Work will continue to raise awareness of the need for Changing Places Toilets, and the £30M funding just announced will make installation a possibility for many venues that would otherwise struggle to install a Changing Places Toilet.



A Changing Places toilet at Tesco Supermarket, Watford



A Changing Places toilet at the Wellcome Collection Museum, London

In addition to progress initiated by Government-led initiatives, a number of UK organisations have unilaterally made significant improvements to their accessibility. One example is Tesco Supermarket: Over the last three years, official Changing Places campaign sponsor Aveso has been working with the food retail giant alongside the Changing Places Consortium to facilitate the installation of a large number of Changing Places Toilets throughout Tesco's network of stores. The project culminated in a celebration of the opening of their 100th Changing Places Toilet in December 2020.

It is also really exciting to see the international growth of Changing Places and we hope to use our experience to help fast-track the roll out of these facilities in other countries.

ABOUT AVESO

As official sponsors of the Changing Places campaign, the team at Aveso are passionate about creating spaces which provide a safe environment for people with additional restroom needs. They can help every step of the way; from initial advice on feasibility and funding, to planning and design, through to installation.

Accessible Travel

Limitations in any form should not keep you from seeing the world, and having a family member with unique travel requirements, should not exclude *you* from traveling!

Accessible travel becomes more important every year. An Amadeus report on Accessible Travel says: "Millions of people with accessibility needs around the world want to travel more, be better connected, and have greater variety of personalized travel services and destinations. Above all, they want to be considered as *travelers* first, with the ability to plan, search, book and purchase their travel independently"

Travel spending in the disability sector has risen by 27% over the past 13 years and continues to rise with more destinations realizing the importance of having facilities that can accommodate everyone. Travellers with mental, cognitive or physical conditions desire and can share similar experiences as *every* traveller such as dining out, visiting the beach, sight-seeing, cultural explorations among other things. Be it cane users, slow walkers, hearing/sight impaired, wheelchair users etc., travel should be for all, and enjoyed by all.



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"I am on a crusade to find competitive employment for people living with disabilities. No matter where you live in the world, if you have a disability, you are my brother or my sister. Remember people with disabilities "Need Paychecks, not Pity."
— Joyce Bender

Meet Joyce Bender

Disability rights champion.
Change-maker. Business owner. Friend.

"Joyce Bender is someone you need to know. I first met Joyce Bender in 2009 when I joined the Board of Directors for the American Association of People with Disabilities (AAPD). Joyce was a fellow Board member and also a mentor. Over the years we have worked together on many issues facing people with disabilities while serving on the AAPD Board. Joyce is a tour de force in the disability rights community and a successful business owner, Bender Consulting Services. She's tenacious, persistent, and gets things done. Through her work on disability-serving Boards and through her business, she's changed the lives of countless individuals and their families. I'm proud to call her a friend and a colleague. I sat down with Joyce recently and asked her a few questions ~ *Fred Maahs, Jr.*"

A few years ago you began the Bender Leadership Academy, tell us about it
The Bender Leadership Academy was started two years ago. It is a for-profit company where we teach high school students with disabilities about the world of work and how to deal with bullying. The academy is not yet offered internationally. Bender Consulting Services is a for profit company with different lines of businesses which include Talent Programs, Strategic Planning, Digital Accessibility, Executive Search and our software product, iDisability.

How did you become interested in helping people with disabilities?
My first close interaction with a person with a disability was Jim Homme, a person who is blind and is today my employee. After meeting students like Jim at a Community College, I found out how terrible the unemployment rate was for people with disabilities and that started me on my current journey.

When did you first experience a tonic-clonic epileptic seizure, and how did you deal with it? How do you manage your Epilepsy now?
I did not know I had epilepsy until 1985 after an almost fatal accident. I did have "faints" off and on as I was growing up, but it was never diagnosed as epilepsy. Today, I am on a medication that pretty much controls my seizures.

You've managed to take your disability and show others that you can still live your life, go to college, and have a successful career. What advice would you give a young person who has a disability and may not realize the future can hold a lot for them.
Never lower the bar. Disability is just part of who you are. It does not define you. Disability is a culture, not a medical model.

You've traveled quite a bit as a person with a disability. What are some of your most memorable, or perhaps, most educational trips you've taken?
Indonesia, Japan, South Korea, Panama and Kazakhstan, at the request of the US. State Department. The purpose of those trips, at the request of the country's embassies, was to discuss the employment of people with disabilities. They were all wonderful and informative trips where I left wanting to take home everyone I met. I also am doing virtual presentations for Tunisia and Libya.

We believe that disability rights are human rights. In what ways should our government do more to help people with disabilities live more independently?
I wish the government would enforce Section 503 of the Rehab Act Prohibits employment discrimination against qualified individuals with disabilities. Without employment, people with disabilities will never live the American dream. I also wish they would enforce Section 508 so all people would have access to websites.

When you're not working to improve the lives of people with disabilities, what do you like to do in your spare time?
I enjoy cooking, gardening, reading and fly fishing. I also love bird watching.

email: Jbender@benderconsult.com
Twitter: @jobsbender
LinkedIn: Joyce Bender

Lil E Coffee Cafe

Inclusive Employer





Photo Credit: Kiki Davies

When the Cafe was opened?

Lil E was officially opened up February 4th, 2021. It was late 2018 when Lil E Founder/ Director Paul Constance visited Washington, DC while attending a EO Global Leadership Academy event. On this same trip, a colleague shared with him of a café in the USA which is staffed by individuals with Down syndrome.

The experience hit home, as Paul thought of his darling baby girl Ella who was born with Down syndrome. What about when she gets older? Would she have meaningful opportunities in life? Back at home, research showed a large percentage of adults with developmental disabilities in Canada are not in the workforce; not successfully finding paid, consistent work even though many are willing and able to work. Paul and his wife Alana (Ella's Mom) didn't want that to be the case for Ella. For anyone.

Paul wanted to show Ella and her brothers that in life, you can make a difference and need to take action. From there the idea of Lil E took off, and pieces of the puzzle magically fell into place.

Along this journey we have been shown immense generosity and learned a true sense of community. We accept and celebrate everyone. We have SO much fun! We are paving a new way. What makes us different, makes us great, and at Lil E we are brewing greatness. This starts with belief that each person has what it takes to be great.



About the business model:

In the beginning when we started researching, we learned many Canadians reported that their disability had created barriers to employment. We felt it was time to make a change. We wanted to facilitate not just a job opportunity, but a journey for people with intellectual and developmental disabilities to build meaningful and long-lasting careers. In turn creating a more accepting and inclusive community.

When Lil E team members are ready to further apply their workplace experience (not necessarily limited to one year), we will connect them to future opportunities with the "Lil E Roasters". These are our corporate friends who have shown interest and support in Lil E. These wonderful corporations share in our values and are aligned to hire Lil E employees and/or candidates in our pipeline, to further break down these barriers and create awareness/acceptance.

With this model, our BHAG (Big Hairy Audacious Goal) is to build 10,000 careers. We are always on the lookout for potential employers for a Lil E "graduate" and encourage interested corporations to contact us for more info on the program.

To Table of Contents

What will you say makes working in your café a rewarding job for your staff? How do you create a safe, welcoming environment for them?

In a short time, we have created a fun and welcoming workspace and culture. From the very beginning in our initial interviews, we stressed our number one rule is to have FUN working. You will see a sign on our café door as employees come into the workspace which says, "Show Time, Have FUN".

You will find our employees smiling, or even dancing, while they make your drinks. Our legendary Friday Dance Offs have gone viral on social media. Customers consistently comment that coming to Lil E, and experiencing our employees' genuine joy and positive nature, instantly brightens their day.

Research indicates nearly two-thirds of adults with a developmental disability in Canada are not in the workforce, even though many are ready, willing and able to work. This is the first job for many of our employees and we want them to enjoy the experience and be comfortable as they build their confidence and life/ employment skills starting their career journey.

With the help from a couple of volunteers (aka Lil E Angels), our core team learns how to do all the tasks/activities in our café, from running the POS system, making the drinks including latte artwork, customer greeting, baking and prep food, taking inventory, etc.. This is important to us that our staff take on all responsibilities no different to any other employee, in order to have meaningful employment. We would never want any employee to feel limited to simple tasks, as we want each person to expand their skills and understand their true ability, for themselves, and how they can contribute within the community.

Also, starting out it was important to us to have diversity in our organization. We currently have 10 employees, five staff members with Down syndrome and five with autism. This daily exchange amongst our staff members has created a unique experience for collaboration to learn from one another; it builds on individual strengths and helps identify potential challenges to focus on going forward. It is quite beautiful to witness the synergies and team work among our staff, and this positive environment extends into the customer experience.



Founder, Paul Constance, wife, Alana and daughter, Ella
Photo Credit: Kiki Davies

What are some of the positives your employees bring to the café?

I joke you don't need a coffee when you come to Lil E, as it's hard not to feel a rush of energy when you meet our staff. They are always smiling and just happy to be there. They care most about those around them being happy and are grateful for the opportunity. Our employees work hard, and they have fun. It is truly infectious. During these challenging times, as the world continues to cope with Covid, this has been very refreshing for all of us.



Darby Taylor
Photo Credit: Kiki Davies

"I was really happy to get this job. It was the best Christmas present. It's been really hard for me to find a job. I have been trying to find a job since 2013. It gives me confidence...in greeting the customers. They're so patient with me. Having autism is a hard challenge for me."

Rhiannon Taylor
Photo Credit: Aaron Reimer

"I love this business and what Paul provides for us and I am enjoying the company of customers and a place to enjoy coffee, and knowing that it's really good coffee, and you'll come back."

With regard to looking for work/finding a job, Shelby Zawyrucha said:
"I don't like in person interviews because when they see me, they always reject me."
To see Ella (Lil E) running around the café:
"It inspires me when you see her walking around, it reminds me of me."



Shelby Zawyrucha
Photo Credit: Aaron Reimer

To Table of Contents

Desirability and Disability:
Role of Adaptive Lingerie and Community

by Emma Butler, Intimately

For many women, purchasing and wearing lingerie is no longer solely about pleasing sexual partners. Instead, it has grown into a form of self-love – an experience that helps define our sense of femininity, personal identity, and self-assurance. Who doesn't feel an extra boost of confidence wearing their favorite set of lacy underwear? Even if no one else sees it, wearing something for yourself that makes you feel powerful, bold, and sexy can have a huge impact on self-confidence.

Everyone deserves that boost of courage, and while I love the push towards more size-inclusive lingerie with companies such as CUUP or ThirdLove, there are hardly any brands creating disability inclusive intimates.

Most disabled folks are all too familiar with the struggle of finding adaptive outerwear that is both fashionable and functional, and this becomes even more difficult when it comes to finding adaptive intimates.





My name is Emma Butler and I am the founder of Intimately, an accessible lingerie brand and community space for women with disabilities. I was first introduced to adaptive apparel after my mother, my role model and a self-proclaimed fashionista, was diagnosed with a few different autoimmune diseases that left her disabled. Together we tried to find clothing that matched her style while also accommodating her newly limited mobility. Sadly, whenever we typed "adaptive underwear" into the Google search bar, all we could find were ugly, medicinal intimates. It was anything but stylish, mostly modelled on elderly people, and the opposite of sexy. In my mom's words, she described the experience as "dehumanizing."

As I entered college, I met many women with different and similar disabilities as my mother. They all shared the sentiment that shopping as a disabled woman is incredibly difficult. Whether because of annoying hook and eyes, tiny zippers, or buttons that require sharp hand dexterity, my disabled friends clearly saw that mainstream clothing brands create items without their needs in mind. They felt unseen and unheard. This is why fostering a supportive community is equally as vital as creating more accessible products.

Today, thanks to social media we can connect with people who have the same diagnosis as us within seconds. Many disabled activists unabashedly share their experiences on social media like a diary that shows who they are instead of only portraying the good days or best sides of themselves. Connecting with people who understand disability and chronic illness, and who have experienced the same ableism and challenges as you have is vital to feeling seen and connected to those around us.

This sense of community is a big aspect of Intimately as well. Our community page offers a space for women to connect and share their thoughts on anything – from sex and dating, to self-love, to travel hacks. All of us are beautiful, and a little boost from accessible lingerie along with a supportive community behind us can make all the difference.

Author bio:
Emma Butler is founder and CEO of Intimately, an inclusive lingerie brand that aims to empower disabled women through fashionable and adaptive undergarments. She is a '20 Brown University graduate and currently a candidate for her MBA at Duke. Any given day you can find her drawing and painting, learning how to cook something other than her famous mac & cheese, or reading a mystery novel.

Instagram: @intimately
Website: www.intimately.co

To Table of Contents



Universal Accessibility Through Her Lens

Maayan Ziv
of
Access Now

The photo shows a thoughtful, resolute gaze. It looks past the camera and silently asks why you think of her differently. It challenges your beliefs and expectations that are perhaps based on erroneous assumptions that usually accompany the sight of someone who sits in a wheelchair. That resolute gaze belongs to a confident entrepreneur, photographer and disability advocate. She is passionate, driven and committed to helping millions of people around the world who live with disabilities confidently navigate their way around the places they choose to go. She is Maayan Ziv and lives with muscular dystrophy, but this has not prevented her from being a positive role model, sought-after speaker and phenomenal woman.

Through her own lens, Maayan tells a story of advocacy, love for photography, and her bold vision for a truly inclusive and accessible world. She shares how photography provided her with subtle opportunities for advocacy that sparked, among other things, the creation of AccessNow, an app that maps accessible venues around the world.

Mélange: Tell us about your photography and journey to advocacy.

Maayan: One of the things I loved a lot about being a photographer was the fact that I was carving out a space for people with disabilities by existing in an industry that didn't expect me to be there and didn't really want me to be there (this is often how it felt). A lot of time was spent convincing people that I could do the job or educating them. I loved being able to reach people and change their ideas about disability; I loved creating space and an awareness that other people could enter the photography industry, see me and think it's possible. That's where my advocacy really started: as a part of my identity, as opposed to [me] fighting for ramps to be made or asking people to do things when I traveled.



Mélange: What led to the creation of AccessNow?

Maayan: In the first week of my masters in digital media classes at Ryerson, we were supposed to go to a restaurant to celebrate the beginning of the year, and I realized that I didn't know if the place we were going to was accessible. This problem had presented itself to me all my life; now maybe there was an opportunity to understand the issue not only on a personal level, but also on a policy level. I started building a business which became an axis just by the sheer need to solve my own problem, and then as I worked on it, I realized how much potential it had to help millions around the world.

Mélange: How does the platform work?

Maayan: We have a mobile app and a website and you can use it anywhere in the world.

It's open, so anyone who joins the platform in our community can contribute their own ratings, like if you went somewhere and thought, "Wow. I never realized how great the accessible washroom is here." If you are somewhere new and don't have anything showing up on the app, you could search for a place and add your own review about it. That's how it grows: within their own communities, people contribute their own knowledge and experiences. The information is shared all around the world, which helps the entire community.

Mélange: How has Covid affected AccessNow?

Maayan: A lot of AccessNow is about helping people get out of the house and find accessible things to do, places to go, and cities to visit. That has obviously changed. Everyone is at home. Nobody's really going anywhere, especially the disability population. We had to change our understanding of accessibility to include things that were accessible from home (like delivery services and virtual experiences). We also had to focus on safe outdoor things like parks and trails experiences that are safe and still provide opportunities to get out and invest in mental health.

Mélange: What are you working on now?

Maayan: Accessibility outdoors and we've been looking at Accessible Trails across Canada. A lot of people with disabilities are sharing different trails that are accessible and also, people without disabilities are talking about the importance of going outside, hiking and discovering new experiences. We recently announced our partnership with Trans-Canada Trail to identify accessible trails across the country.

Mélange: What are some of the strengths a person with a disability brings to an organization?

Maayan: Most people in the workforce don't understand our value. They're afraid or see us as just a liability. Yet, one of our most important [qualities] is resilience: we constantly have to problem-solve in our own lives and bounce back. Our ability to constantly cope with challenges and be flexible are the kinds of skills that most employers look for, so I find it funny that people don't make that connection. Since I was 6 years old, I've had to problem-solve just based purely on the number of skills and exercises I've had to work through, so I naturally offer a skill set lacking in somebody who didn't have those challenges. This is a lost opportunity in the employment space because people don't realize that it's such a great asset to have someone who's naturally more entrepreneurial.



Maayan advocating in the community - photo credit: Kevin Bryan

Mélange: What do you think people can do right now to be more accepting and inclusive of people with disabilities?

Maayan: The number one thing people can practice is active listening and openness to being comfortable with things that are different to what they are used to. People get really comfortable with what they know, which often leads to being surrounded by people who look, think, and do like them. Accountability is also important. Having the understanding that every person is responsible for ensuring that our world is accessible pushes us toward a world that is inclusive. Also, I think there should be more personal drive to ensure that people are educated about disabilities. Although I may choose to do so, it's not my responsibility to educate others. As it relates to inclusion, people just assume that if you have diversity, you'll have inclusion. It doesn't work that way -- you have to work for inclusion.



www.accessnow.com

To Table of Contents

My return to Dubai. Even more amazing than my first trip!

ACCESSIBLE DUBAI

by Fred Maahs, Jr.

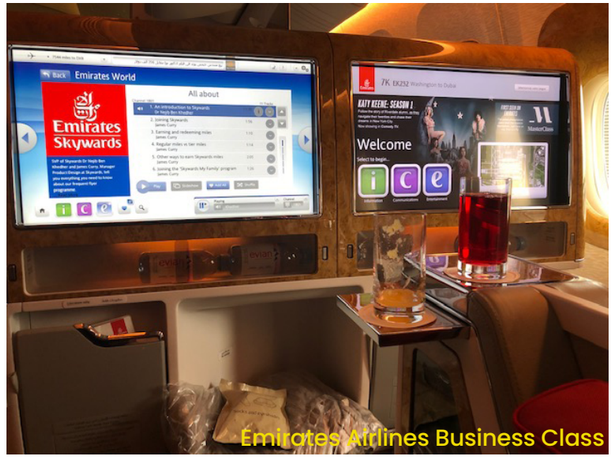
Recently I had the pleasure to return to Dubai as a guest of Dubai Tourism to help assess accessibility for people with disabilities, also known as "people of determination" in Dubai. I was there in three capacities; consulting for my own business, FJM Solutions, as Chief Operations Officer and partner for Travel for All, and as Editor of Mélange Accessibility for All magazine. I was joined in Dubai by John Sage, his wife, and their colleague, all with Sage Travelling.

The trip began with an Amtrak train ride from Wilmington, Delaware to Washington, D.C. at 5:00 AM. I've taken Amtrak from Wilmington to Washington hundreds of times but this was the first time I "opened" the station in Wilmington with a police officer unlocking the station's doors to let me, and upon my arrival at Union Station in Washington, found it basically empty at 7:00 AM on an early December morning! From there it was a 40-minute accessible cab ride, (thanks to *Union Cab*) to Washington Dulles International Airport.

Even at 8:00 AM, the airport was fairly quiet for what is normally a busy travel time. Smaller crowds and quicker lines through TSA made it feel like I was in the "Bob lane" – but thankfully less people were traveling and were being more cautious due to COVID travel restrictions, as they should have been. I had to take a COVID test and have negative results no more than 3 days before departure, followed by a COVID test once there, and another 3 days after my return. I didn't mind the extra precautionary steps. I would have taken even more if it meant I was more likely to travel safely.

My flight was at 10:30 AM so I had some time to catch up on emails and the latest news. When it was time to board, I had assistance from two very helpful airport agents as well as an extremely helpful crew to board the ***Emirates Airlines*** 777. I flew Business-class for the 14-and-a-half-hour direct flight to Dubai and remembered that my flight a year before was also Business-class. The incredible amenities provided by Emirates Air is beyond compare, but the extra room in your "lay-flat" seat is especially important and helpful for people with disabilities. As a paraplegic, it helps reduce the chance of DVT, or Deep Vein Thrombosis (blood clots – especially in your legs).

Once you get to your seat, which feels like a private sanctuary, the crew immediately is "at your service" wanting to do all they can for you to have a pleasant and safe flight. This time, I was provided with plenty of PPE – gloves, hand sanitizer, a mask. Fortunately, I had brought an ample supply of my own PPE for the trip. The crew introduced themselves to me and I soon had a beverage in my hand and was ready for takeoff! I felt safe. I felt happy. I was too tired to be tired – you know, kind of like when you're a kid on Christmas Eve and you're so excited to wake up the next morning you can barely sleep! And, I was excited – excited to return to Dubai and to have the opportunity to explore so many new things.



Emirates Airlines Business Class


Dubai Airport


Emirates Airlines Meal


Westin Dubai Lobby

The service, attention to detail, the meals, and the beverages on board the flight to Dubai were all impeccable, right down to the fresh flowers delicately placed in sconces on the cabin walls. Once we landed in Dubai the next morning, a familiar song began playing over the plane's speakers. It was none other than Mariah Carey's, "All I want for Christmas." I couldn't help but to smile.

The Dubai International Airport, or DXB for short, is the largest airport I have I ever seen. It is simply massive, and the cleanest. I was greeted by representatives from Dubai Tourism who helped me breeze through Customs and luggage and quickly to accessible transportation. The ride from the airport to the hotel was about 40 minutes and my driver, *Mr. Ihsan-ullah Umar Farooq*, and his colleague, *Mr. Mehul Bulsara,* who would be the tour guide for the week, were quite friendly. I remembered our driver and kept looking him and realized I knew him. As we arrived at the ***Westin Dubai Mina Seyahi Beach Resort & Marina,*** he assisted me to the ramp and turned and said, "Mr. Fred?" And I replied, "Yes! Umar, I knew it was you!" He was my driver a year ago during a business trip and presentation for the inaugural Dubai Accessible Tourism International Summit. It was so good to see him again! And, it was good to be back in Dubai.

Upon entering the hotel, a Westin hotel employee was taking the temperature of each person entering the lobby as


Westin Dubai Beach

a precautionary measure for COVID. Anyone with an elevated body temperature would be asked to speak with a hotel supervisor to understand what measures would be taken to ensure everyone's safety. After check-in, I was shown to my room which was down a long hallway and then an elevator to the first floor. Anxiously I opened the door to my suite and found a spacious room that I could easily navigate my wheelchair around. The bed was at the appropriate height, (23-24") so I would not have issues with transferring from my wheelchair to the bed and back. The bathroom was large and had a roll-in shower and a huge soaking tub. The sink and vanity were accessible and there were grab bars in the shower and around the toilet.

The room also had sliding doors that led to a 20'x20' large open-air veranda which was covered and ramped to the grass which led to a sidewalk. I was facing the beach located beyond the trees and walkways which blocked my view, but nonetheless it was easy to get to.


Westin Dubai bathroom

I was able to unpack some things easily and the iron and ironing board were easy to access safely. I pressed off a few dress shirts then went off to meet my friends and colleagues who are based in Dubai, *Nawal* and *Ali,* for a coffee at one of the outside restaurants. We sat at a beautiful and accessible table and caught up on business, life in general, and what the next week would have in store for me. And, the coffee was delicious, too!

After Nawal and Ali left for other business, I took some time to explore the beautiful and accessible grounds of the Westin. The property is massive and is located right on an expansive beach. While there were not large crowds of people there, there is plenty of room for sunbathing and activities, including lots of water sports.

The summer months can get quite hot in Dubai and the Westin has plenty of pools and shade trees to stay cool. I would like to return to the Westin in early or late summer to enjoy all of the outdoor amenities they offer.

During my walk, I could see new construction in every direction I turned – everything from new office buildings to new condominiums to new hotels. The amount of building taking place since the last time I was here a year ago is incredible. More about that a little later. The property next to the Westin under construction is the site of a new waterpark, Jungle Bay. It has since opened and will be a huge attraction for people of all ages.

The next day was a free day for us, so I had a late breakfast in the lobby restaurant and decided to go outside to enjoy the fresh air and the warm sunshine and to explore the hotel property. People were already enjoying the beach and the warm water as well as the pools at the hotel. While relaxing by one of the pools, I caught up on emails in the shade and enjoyed a few beverages. A few hours later, I decided to try the ***Fish Beach Taverna restaurant,*** part of a shared property with ***Le Meridien hotel*** next to the Westin, on the beach which specialized in Greek and Turkish food from the Aegean Sea, the Black Sea, and the Marmara Sea. It was a beautiful setting, all open air, shaded by palm trees. The main seating area was accessible but it may be a little tricky to be seated at a table on the grassy area. It felt like I had escaped to a Greek isle. My server was quite friendly and helpful and as I enjoyed a freshly made glass of Sangria, I was able to select fresh seafood from a display of prawns, lobster, fish, squid, and octopus. I selected three very nice prawns and asked that they be grilled. Wow!

but impressive menu and an extensive wine list. I enjoyed a fresh tomato and mozzarella salad and homemade pasta for dinner with a glass of Cabernet.


Bussola restaurant


Fish Beach Taverna restaurant

You must try this restaurant while in Dubai!

After lunch I went back to my room to rest and to catch up on news and emails. Later that evening I decided to try the ***Bussola*** which is the hotel's Italian restaurant. Chic, upscale décor with a bar area and outdoor dining if you choose. All of the restaurant was accessible but I did not see any menus in Braille. It had a simple

My server was from the Philippines and she made sure everything was just right for my meal. This is another restaurant I would recommend that you try!

Breakfast was served early the next morning and our first meeting began at 9:00 AM. We met with representatives from Emirates Airlines and the Westin hotel to discuss travel packages, accessibility for people with disabilities,

and overall impressions so far. We also met with *Dr. Jennifer Camulli,* a friend and colleague, but more importantly an expert in the area of inclusivity, especially as it relates to people with disabilities (people of determination). Dr. Camulli is responsible for the oversight of accessibility and inclusion at the World Expo 2020 being held in Dubai beginning in October of this year (postponed a year due to COVID). Dr. Camulli spoke with us about accessibility and inclusion and her approach to work across all groups involved and responsible for a successful Expo, and how accessibility and inclusion are intertwined and a common thread for each area.



Dr. Jennifer Camulli

After our presentations we were taken to a part of old Dubai to visit the ***gold and spice souk market.*** This is much like the "farmer's" markets or places where artisans and others sell their produce, spices, and wares, with one exception – part of this souk market was high-end and selling gold and jewelry. We navigated through the

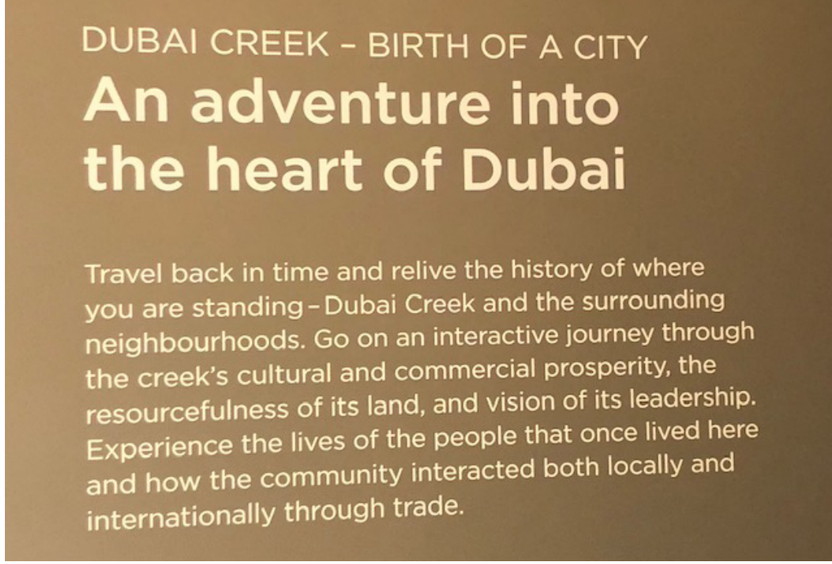

Gold & spice Souk Market

market fairly easily though a number of the stores had a single step to enter – so if you use a wheelchair or have a mobility impairment you will need help. I purchased some ginger, saffron, and a higher-grade frankincense. Who knew there were different grades of frankincense?

After our souk market visit, we left for a cultural lunch experience at ***Al Bait Al Qadeem Emirati Heritage Restaurant***. We were greeted by the owner and his staff who showed us to a long wooden table. He was dressed in traditional clothing and explained the meaning of this type of clothing. We also about the history of the area and the types of food available and how the United Arab Emirates had traded pearls with other countries for spices and textiles – all helping to make the UAE and Dubai

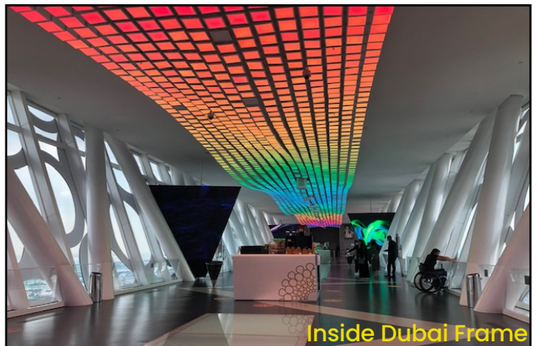


what it is today. After lunch, we transferred to the ***Al Shindagha Museum***, also in Old Dubai. The museum is located next to Dubai Creek and is very accessible and while not large, it is very modern in design and gives a thorough history of Dubai. Each of the rooms within the museum are accessible and even has some "hands on" displays.




Al Shindagha Museum


Al Fahidi District


Inside Dubai Frame

From the museum, we were taken in a guided tour of the ***Al Fahidi District*** and learned that this is really where Dubai "began" – as a port for pearl divers with pearls as the primary "industry" for trade.

We left the Al Fahidi District to return to the Westin. It was late afternoon and yes, Dubai does have traffic. We had time to freshen up and relax for a short while before our on-site dinner at the Westin. We met at the ***El Sur restaurant*** which specializes in traditional Mediterranean food with lots of shared plates, or tapas. Accessible and spacious, we dined in a covered area outside and enjoyed a delicious meal.

The next morning we checked out of the Westin and we left for the ***Dubai Frame***. The Dubai Frame is a unique "building" which looks like a giant picture frame, and is claimed to be the largest picture frame in the

world. It stands about 493' high and about 305' wide. It only takes 75 seconds to reach the top of the 48 story structure after you purchase your tickets. **An interesting piece of information:** *people of determination (people with disabilities) do not have to purchase a ticket for museums and public structures like this in Dubai and can bring up to two guests at no charge.* Once there, the glass walls and glass floor provide you with views of Dubai. One side of the "Frame" gives you a view of Dubai's "past" with the older buildings and the original seaport, and the other side gives you a view of the "modern" Dubai with its magnificent skyscrapers and glass buildings. The Frame is totally accessible and is an interesting spot for tourists to visit!


Dubai Frame

After our visit to the Dubai Frame, we were taken to the ***Etihad Museum***, historically known as the ***Union House.*** The Museum is an incredibly modern, accessible building with the rich history and artifacts, artwork, and displays of the United Arab Emirates inside. It begins with the stories of the seven Founding Fathers, each representing the seven Emirates and how the Emirates became the country that it is today. For an in-depth and visual understanding of the history of the United Arab Emirates, you should put the Etihad Museum on your list


Etihad Museum

to visit. From the museum, we drove about 30 minutes to the ***Jumeirah Hotel Complex,*** situated directly on the Arabian Gulf and part of a group of luxury hotels owned by Dubai Holding, with its majority shares owned by Sheikh Mohammed bin Rashid Al Maktoum, the Ruler of the Emirate of Dubai, and the primary founder of Dubai Inc. We toured a few of these resorts, each with its own style and "vibe" and all luxurious. For the most part, each resort included properly adapted and accessible rooms, with the exception of one of the resorts. If we had more time, we could have also visited the famous ***Burj Al Arab*** – claimed to be a 7 Star Hotel. There is a man-made river which runs through all of the properties so you can move from one resort to the next by boat, kind of like a gondola, or you can use the wide walkways to navigate the complex. All of the walkways are accessible, right down to the beach, but the boats may be a little more difficult to navigate if you use a wheelchair or have mobility issues. We were treated to an unbelievably delicious lunch at the complex at the ***French Riviera restaurant,*** on the ***Jumeirah Al Qasar hotel*** property, that was situated right on the beach with incredible views of one of the large pools on one side and the beautiful Arabian Sea on the other side. Just spectacular!


Jumeirah Complex Waterway

We could have spent the rest of the afternoon and evening in that little oasis, but had to leave for a 45 minute ride to the famous ***Dubai Miracle Garden***, located in the ***Dubailand*** district of Dubai. The garden boasts the world's largest display of more than 50 million flowers which grow, and are displayed, on figures such as an Emirates plane, Disney characters, hearts, and various other statuary. The Garden is ramped and accessible and there are a few places to purchase food and drinks.


Dubai Miracle Garden

Our next stop was to check into the ***Oberoi Hotel,*** a recently updated and modern hotel with views of the ***Burj Khalifa.*** Check in was quick and easy after we had our temperatures taken. The Bellman helped with my luggage and we took the elevator to my room, a spacious and accessible space on the 6th floor. The room had


Oberoi Hotel Lobby

To Table of Contents


Oberoi Hotel Bedroom


Oberoi Hotel Bathroom


Oberoi Hotel Bathroom


Royal Atlantis Hotel Lobby

floor to ceiling glass windows and the bed was positioned to the proper height for easy transfers. The bathroom was quite large with a long vanity and double sinks, one of which was accessible. The roll-in, full-glass shower was large but did not have a flip-down bench, just a very small portable shower seat. A large soaking tub with jacuzzi was situated next to the shower, and the bidet and toilet was directly to the left of the shower with a glass wall fixed just a little too close to the toilet which made it a little difficult to use, but manageable. I was able to use the shower-commode chair I had purchased to access the toilet and the shower.

After a quick freshen up and a few minutes to relax, I had to meet with my colleagues Ali and Nawal from *Massiraa* to participate in a panel discussion about accessibility and travel. After the panel discussion I met the rest of my group in the hotel lobby for a tour of the pool area followed by a delicious dinner in the hotel at ***Nine7One restaurant*** which specialized in Arabic, Asian, and Western cuisine. The restaurant was accessible and the servers were very helpful.

The next morning we had breakfast in the hotel restaurant and then drove for about 40 minutes to the site of the ***Expo 2020 Dubai.*** The location is a massive area, almost 1,100 square acres, with a direct rail line and highway built to access it. There are 192 Pavilions representing each country that is participating in Expo 2020 Dubai. This World Expo will be the most inclusive and international Expo ever! It's also estimated the Expo will have created 277,000 new jobs by the time it ends. The Expo will have a theme called *"Connecting Minds, Creating the Future"*. The Expo will also have three subthemes: *opportunity, mobility* and *sustainability*, each with its own pavilion. Each of the pavilions was still under construction. We met with my friend and colleague, Dr. Jennifer Camulli who led us on a tour and described the attention to detail given for accessibility and inclusion for all people. The Expo is beautiful, modern, unique, and of course, fully accessible so that everyone may enjoy it. The Expo runs from **October 1, 2021 through March 31, 2022.**


Expo 2020 Dubai

When we concluded our tour of the Expo we drove about 40 minutes to ***Atlantis, The Palm*** - a 1,548 room ocean-themed destination resort, spectacularly situated on the crescent of ***Dubai Palm Island*** with views across Dubai's iconic skyline. We met with a delightful representative of the Atlantis, Nerissa Ronquillo, who is a Manager of Sales. She took us on a tour of the Atlantis, including an accessible room with a beautiful view of the beach. The room was planned well and had the appropriate height of the bed, grab bars in the shower and around the toilet, and the sink height was at a comfortable and accessible level.

The property at the Atlantis was quite large, complete with an enormous pool, beach, and a gigantic aquarium with more than 65,000 marine animals. It also now boasts the world's largest water park! The resort has a number of restaurants to choose from and we were treated to a delicious lunch at ***Gordon Ramsay's Bread Street Kitchen and Bar.*** This is a place for all to enjoy and quite easily accessible. I hope to be invited back to experience all of the amenities and accessibility the Atlantis Dubai has to offer!

We left the Atlantis excited for our evening excursion, a desert experience provided by ***Platinum Heritage***. It was about an hour drive from the Atlantis to the desert. We loaded into vintage 1950's Land Rovers and ventured through the ***Dubai Desert Conservation Reserve*** and saw native wildlife including Arabian gazelles just before sunset. It was beautiful! We stopped for a short while for a demonstration on falconry. It was quite interesting to see how they are trained and to learn how falcons have been used to hunt over the centuries in the desert. We then proceeded to an authentic ***open-air Bedouin camp*** sheltered by tents and seated on ***Arabic Majlis*** for our traditional three-course dinner of chicken, Australian filet steak, and vegetable moussaka. We enjoyed enjoyed traditional music and drum beating. It was magical being in the middle of the desert in total darkness and looking up at the stars with each bright, twinkling light appearing so close yet so far away.

After breakfast at the hotel the next morning, our guides took us to the ***Dubai Mall*** where we parked and navigated through the mall to the entrance of ***At the Top Burj Khalifa.*** The Burj Khalifa is the tallest building in the world with an absolutely amazing view of Dubai, Abu Dhabi in the distance and of course the Arabian Sea. After our tour of the Burj Khalifa we had some time to spend in the Dubai Mall. Some of the restaurants and shops were very familiar, such as McDonald's, Pottery Barn, and even a Hallmark Card store. I even passed by a Five Guys hamburger stand.


Observation Floor at the Burj Khalifa


Open Air Bedouin Camp

We left for a very quick ride to the ***Address Boulevard hotel.*** The Address Boulevard is an absolutely amazing luxurious hotel located very close to the Burj Khalifa. Exquisite infinity pools and luxurious restaurants and accommodations, as well as being connected to the world's largest shopping mall, ***The Dubai Mall.*** The hotel offered beautifully appointed accessible rooms that were spacious, included grab bars, and a small balcony. We had a delicious lunch at the hotel, hosted by one of the managers. After lunch, we then took a short ride to the ***Palace Downtown hotel,*** another Address Hotel property. This was another luxurious property that is built on the edge of the man-made lake on ***Old Town Island*** but felt like it was in the middle of an oasis - not in the center of Dubai. Such an elegant but practical property that included accessible guest rooms with accessible bathrooms.

We drove back to the Oberoi Hotel and had some time to freshen up and catch up on emails before we left for our evening entertainment, ***La Perle***. La Perle is just a few minutes away from the Oberoi hotel in ***Al Habtoor City***, an entertainment district where there are lots of venues for shows and music. The show is the first permanent show in Dubai and features over 65 world-class performers. Its venue was quite accessible with special designated seating for people of determination, with food and beverages available to purchase. The show is very similar to the Cirque Du Soleil shows that take place all over.


La Perle

After the show we were transferred back to the Oberoi for our last night in Dubai. It was late, but I had enough time to pack and get ready for my early departure the next morning for Dubai International Airport.

While this was only my second visit to Dubai, I really did not want to leave. It's such a beautiful and intriguing place. More than 80% of the people who live there come from other countries, so there is this unique blend of cultures that seem to work together. Everyone that I encountered and met with, each place that I visited, made me feel welcomed. And that's the beauty of Dubai, isn't it?

I want to thank my friends and colleagues at Dubai tourism, especially *Soraya Al-Olama,* for their incredible hospitality during my visit. I also wish to thank the representatives from each of the hotels, entertainment venues, and restaurants that went out of their way to provide us with exceptional service. A special "thank you" to *Emirates Airlines,* not only for a very safe and delightful flight, but especially for a friendly and helpful crew that truly made me feel welcomed. To our driver and tour guide, *Mr. Ihsan-ullah Umar Farooq*, and his colleague, *Mr. Mehul Bulsara,* thank you so much for the very early mornings, the very long days, and the late nights. I hope you had a few days off after our tour.

To the Dubai government I want to say thank you for your efforts to help make Dubai an accessible and inclusive place to visit and to live. People of determination appreciate all that you're doing – please know that I do. I hope to be invited back soon to continue our work together.

شكرا لكم والسلام عليكم

shukraan lakum walsalam ealaykum

FJM Solutions, LLC

Fostering Inclusion Universally



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Acessible Indonesia

A candid look at Accessibility in Indonesia for wheelchair travellers

Monkey Forest, Bali. GertLijnes, AI Tour
Photo Courtesy, Accessible Indonesia

A visit to Indonesia is on the bucket list of many travellers. As resumption of travel lurks on the horizon, many people are dusting off these lists and making decisions about the first destination they will visit post-pandemic. For wheelchair users, here are a few things to note about visiting Indonesia.

It is important to get detailed information from tour companies before heading to Indonesia. With the help of family, friends and tour guides, the mobility impaired will find Bali and its main attractions easier to navigate than other Indonesian islands. Bali is considered to be the most wheelchair-accessible, with Jakarta, the capital of Indonesia taking a far second place. Other places such as Yogyakarta on Java is minimally accessible but Sulawesi can be very difficult and it is not advised to visit if you are a power wheelchair user.

Although Bali is the most accessible island in Indonesia, accessible sidewalks are rare and someone will often have to lend assistance to wheelchair users so they can get around potholes and other barriers. It is therefore important to again consult with a tour guide before venturing out, as they will be able to recommend areas where solo wheelchair travellers can safely and comfortably navigate.

When sightseeing outside of the capital, visitors should expect bumpy streets, so be prepared. Another consideration is the heat with temperatures around 28 degrees C (82.4 F) or higher, in combination with high humidity.

Round tours are available in Bali during which you will most likely have to stay in hotels outside Denpasar, the capital. There are accessible hotels in Bali (and Jakarta), but on other islands and cities, the choice is limited and it may be more difficult for power wheelchair users to find accommodation.



Besakih temple & volcano Gunung Agung, Bali
GertLijnes AI Tour

ACCESSIBLE TOURS
Companies like Accessible Indonesia offers individual and group tours which include single day tours or an entire holiday with inclusive assistance. Tours can be booked directly with them or through other specialized travel agencies, such as Travel-for-All. Every tour is customized to guests' specific requirements. Accessible Indonesia conducts accessibility surveys of destinations and hotels in Indonesia, providing guests with detailed information about a location's accessibility prior to their arrival.

ACCESSIBLE TRANSPORTATION
In Bali, you will find minivans with lifts and in Yogyakarta, Jakarta and Sulawesi, minivans with ramps.

AQUA ACTIVITIES
Snorkeling and diving for people with disabilities is possible in Bali with the help of professional dive instructors.

AccessibleIndonesia specializes in visits to Bali, Java and Sulawesi and can assist with the booking of accessible transport and hotel rooms for guests. They can offer advice and support to solo travellers by being in direct communication via phone and email before and during an outing. If required, they will accompany guests on their tours which is often a much-needed service because assistants can provide all-round help throughout the excursion. They also offer a range of appliances guests can request if they are not available at their accommodations.



Monkey Forest, Bali.
Photo Courtesy, Accessible Indonesia


Bamboo Forest, Bali.
Photo Courtesy, Accessible Indonesia

Help is always readily available in Indonesia. Admittedly, there are limitations with regard to accessibility, but the genuine helpfulness of the people to ensure travellers needs are met does help to make stays possible and memorable.

TOUR COMPANY
Accessible Indonesia
Contact: Maureen Maspaitella
Email: accessibleindonesia@gmail.com
or info@accessibleindonesia.org

DIVE INSTRUCTORS
Bali International Diving Professionals, Sanur
Email: info@bidp-balidiving.com

HOTELS
Legian Beach Hotel, Legian, Bali
Email: info@legianbeachbali.com

Gardenia Guest House, Sanur, Bali
Email: gardeniaguesthousebali@gmail.com

To Table of Contents



En Route to a Fully Accessible Barbados

by: Shana Jones

The United Nations Convention on the Rights of Persons With Disabilities was established at the UN headquarters in New York on December 13, 2006 and took effect on May 3, 2008. Its 39 articles outline clear mandates for recognizing and protecting the right of persons with disabilities (PWD) to function in society with the same dignity, freedom, and opportunity as other people. In February of 2013, Barbados ratified the convention, pledging before the world its commitment to uphold the directives of the agreement.

In 2016, the Barbados Tourism Product Authority threw its support behind the Fully Accessible Barbados initiative launched by the Barbados Council for the Disabled (BCD), the umbrella organization for specific and cross-disability organizations on the island. With a view to enhancing the island's tourism product, the program, among other things, established accessibility standards for businesses and facilities serving the public. It goes without saying that accessibility benefits everyone: an enjoyable vacation for some translates into spending power, and in turn, economic activity for others. How does Barbados become fully accessible, though? Surely it means more than putting a wheelchair symbol on the door of a business, and it's definitely not limited to vacationers. What exactly does a fully accessible (or at least one en route to full accessibility) Barbados look like? What are some of the elements moving the island in this direction?



Photo Credit: Fully Accessible Barbados

Advocacy/support groups/ community representation

The Barbados Council for the Disabled seeks at its core to improve the lives of PWD in Barbados. With its member organizations, it endeavours to change the experience of PWD through raising awareness to change mindsets, advocating for legislation and policy that recognize and protect the rights of PWD, working with local business and government to provide improved access to facilities, and with its affiliates, providing specific services and assistance to PWD, including education options and employment opportunities. One of its major projects, the Fully Accessible Barbados initiative, extends the council's mission further to embrace tourism and "aims to create a barrier-free environment in Barbados".

Legislation and international standards

Without any legal framework or regulatory support, the BCD would have very little ability to bring about any change, so in 2012, it pressured the government to ratify the United Nations Convention on the Rights of Persons With Disabilities. Under the convention, PWD are no longer to be viewed as objects to be pitied or exploited; rather, they are to be recognized as beings worthy of the same rights, freedoms and opportunities as people without disabilities. This speaks directly to the treatment of PWD in countries that have ratified the convention, and having done so, Barbados is bound to honour its mandates. At the national level, in 2016, the Barbados Tourism Product Authority started supporting the BCD in its Fully Accessible Barbados program. The tourism authority also jointly worked with the BCD and Barbados Tourism Marketing Inc. to draft legislation around

building codes for accessibility for tourist venues. Blanket legislation mirrored after international standards and the rule of universal design is also in the works.

Efforts to raise awareness and change mindsets

Despite its evolving views of PWD, Barbadian society still harbours some traditional mindsets about this community. Mindsets can only be challenged by raising awareness, and the BCD addresses this through sensitivity training, community events, a number of specialized services, and information sharing through its website and social media. Disability sensitivity training has been undertaken by many public and private service providers on the island, the largest being the Barbados Tourism Product Authority. Training sessions cover the Fully Accessible Barbados program, understanding disabilities, assisting persons with visual impairment, communicating with the deaf, and techniques for lifting and handling people with mobility challenges. The training is conducted by persons with disabilities, therapists, sign language interpreters, and other professionals.

Month of the Disabled, celebrated in March, is perhaps the most significant event on the BCD calendar. Under the theme "Building Back Better for a More Inclusive and Resilient Barbados", the activities this year included the #CookLikeWe challenge, an online art exhibition, a radio call-in program about special education of PWD in the Covid environment, and a television showcase of PWD in artisan training.

In the arena of increasing awareness, BCD shares information about specific disabilities and recognizes exemplary leaders in the community through its website and social media. In February this year, BCD News featured Janeil Odle, the first blind attorney to be called to the bar. Last year, president of the Barbados Horizon Deaf Club Lionel Smith offered a few tips on communicating with persons who are deaf on the BCD YouTube channel.

Improving accessibility

Under the Fully Accessible Barbados program, the BCD assesses properties for their level of accessibility, makes recommendations as necessary, and then awards the properties within its six accessibility categories according to the level of access offered. The Fully Accessible Barbados accreditation program was designed to "enable people with access requirements to function independently and with dignity through universally aligned tourism services and environment."

Specific services

In order for PWD to "function independently and with dignity" in society, certain accommodations must be made. Through the BCD, these come in the form of Braille translation, accessible transportation options, sign language interpretation, beach wheelchairs (for use on land and in the water), designated parking ID's, and an "empowerment" (discount) card for members accepted at merchants across the island.

Education options

A number of learning and training institutions around the island cater to children and adults with disabilities from birth to the age of 21. The services available include academic, rehabilitative, vocational, and basic life skills training, as well as early stimulation and sheltered employment programs.

Employment opportunities

While it remains an unfortunate reality that PWD face higher levels of employment discrimination, the Covid-19 pandemic offers a possible ray of hope: this potential equalizer has leveled the playing field by proving that employees don't have to be at a physical location to do their jobs. Roseanna Tudor, operations manager at the BCD, envisions the "develop[ment] [of] a new norm" in which difficulty accessing a location is no longer a barrier to employment or other services.

Barbados doesn't boast full accessibility yet, but it's definitely on this path and paving the way for other regional destinations to follow. A major step in its progress has been an evolution in thinking that now views persons with disabilities in a different light: as equally valuable resources to be celebrated and empowered and able contributors to an economy now hungry for a turnaround. In such a time as this, no resource can be cast aside. Accessibility opens doors to these resources previously untapped, revealing significant opportunities for growth and enrichment. Accessibility – full accessibility – just makes sense, not simply as a critical factor in a destination's competitiveness, but as a catalyst for true inclusion and development.



Photo Credit: Fully Accessible Barbados

To Table of Contents

Friends of Access Israel



Jamie Lassner

EMT volunteer, General Director of a nonprofit, and much more…

by: Fred Maahs, Jr.

I was introduced to James (Jamie) Lassner by a mutual friend, Howard Blas. It did not take long to realize that we had a lot in common and that Jamie is really a super nice person with a kind heart. I knew that it was the beginning of what I believe will be a lifelong friendship and as we spoke more with each other, on Zoom, of course, I learned more about him. And, I also knew that I wanted to share his story with the Mélange audience. You will understand why after you read this Question and Answer piece with Jamie.

~ Fred Maahs, Jr.

Jamie, where were you born and where did you spend most of your childhood? My only sibling Andy and I were born in Bogotá, Colombia. I was born in 1964 and my bro was born in 1966. My father was working for a US based company and we returned to USA in January 1970. I grew up on the Upper East Side of New York and was blessed with the biggest backyard – New York City's Central Park.

Where did you go to college and what degree did you obtain? I attended Baruch College of the City University of New York (CUNY). I graduated with a B.A. in Finance and minor in psychology.



Access Israel pre-convention accessible tour

What was your first job out of college? My first job out of college was as transport manager for a commodities trading firm in Manhattan. I left that company to become President of a Dutch-based commodities firm in NYC.

What led you to become an EMT? My parents and grandparents were extremely altruistic people. Always teaching us by example. The synagogue we belonged to was the closest to Mount Sinai Hospital. Many of our congregants were doctors. I had the urge to become a doctor, but I was never really fond of being a student, homework, etc. Accordingly, when I found out that there was an Emergency Medical Technician (EMT) course being offered to me and it was 'only 6 months' – I jumped at the opportunity. The first volunteer corps I joined was the Central Park Medical Unit. The ambulance responded to calls within Central Park and covered all concert and events. Soon after, I became one of the original members of an ambulance corps that covers the upper east side of NYC. I have been an EMT for over 35 years – all volunteer.

Tell us about September 11 On Black Tuesday, I arrived at my commodity trading office located just a few blocks south of the World Trade Center. At about 8:45 AM, I was completing a conference call when there was a bang and then the lights flickered.

We went to the back of our offices and saw fire on the top part of one of the Twin Towers. We watched as flames billowed from the windows, not understanding what had happened. We heard on the news that a small commuter plane had struck the World Trade Center. Looking at the large hole it looked a lot bigger than a commuter plane.

> **My parents and grandparents were extremely altruistic people. Always teaching us by example.**

I responded to a citywide call for emergency personnel to help. I was told by the volunteer ambulance dispatcher to head to City Hall that was about 8 blocks north of my office - just North East of the Towers. I ran up Broadway. But, before I had time to think, I witnessed what seemed like a scene straight out of a movie. I saw and heard a plane on full throttle dip its wing and pummel into the second tower. This is a scene that we have all witnessed over and over on TV. Despite viewing it so many times it is hard for me to register it as the reality it was. In the Wall Street area, there were thousands of papers in the air. Pieces of buildings were falling. Watching this debris, it was heart wrenching to recognize that some of the debris were people jumping to their deaths.

As I reached Century 21, a store just across the street from the World Trade Center, there was one of our volunteer ambulances. I stopped and started to assist in treating patients. Suddenly, a blood-curdling scream to run was heard from a firefighter as the first tower started to collapse. I looked up briefly and saw the famed antenna tipping over. We ran a block when the cloud of ashes and debris caught up with us. By the grace of God, we were able to break through a glass door and enter a building to shield us from large falling pieces. In that building, huddled on the ground, I found myself with about 40 other people from all walks of life and with a new view on life.

I was now proudly working

We were from all walks of life, all different trades, and assorted religions, yet we were all simple human beings fighting to survive and help others survive.

with a Hispanic undercover larceny officer, an African American DHL courier, and an injured Catholic firefighter, to help the people inside with us and just outside this building. We were from all walks of life, all different trades, and assorted religions, yet we were all simple human beings fighting to survive and help others survive. We kept each other focused on running for our lives.

We then saw that the flying and scattered metal, paper, concrete, and other debris outside the building was going to be an obstacle course for us. We had a severely injured firefighter and several asthmatic people who needed to be walked to the hospital. As we started making our way out of the building, we heard rumbling again and then we were bombarded with the second tower. We luckily found a parking lot into which we literally dove. It is then that I injured my right leg (later found out I had torn several knee ligaments).

After waiting for about an hour, splinting myself, we finally made our way out. We made it to the local hospital with our patients and then I finally headed toward City Hall to try to find some of my fellow Volunteer ambulance members. I found an Ambulance that took me to Beth Israel Hospital where I had my eyes washed out as I was covered in ash. I got a better splint and continued my service, as this was a catastrophic event that needed responders.

In the days following Black Tuesday our crew was stationed on the west side of ground zero at the entrance to the World Financial Center. We had the opportunity to work with and meet members of the Federal Emergency Management Agency's search and rescue teams. We were working with men and women and their specially trained dogs from all over the USA.

We were all Americans looking for and hoping to help fellow Americans and people from other nations. Unfortunately, as time went on, we realized that we were looking to recover the remains of fellow human beings and we did what we had to with much respect and dignity.

I recall seeing three McDonald's refrigerator trucks and was impressed that they were sending down food to the other rescue workers. To my chagrin, I was told that they were empty and were being used as a temporary morgue.

On October 11, well after the swelling subsided, I had reconstructive knee surgery and on November 11, I was diagnosed with severe Post Traumatic Stress Disorder (PTSD).

At what point and how did you become involved with Friends of Access Israel? What was the deciding factor to take on the role of Executive Director?

After rehab for my knee (have had 3 knee surgeries on each knee since) and more importantly therapy for PTSD (which I still have – but managed) – over a period of time I realized that making money at commodities was wonderful but was not fulfilling my inner desire to make the world better. Obviously, I was not in a position to fight the terror that attacked the world on 9/11, but I was in position to double or triple up my good deeds to counter the evil. I was granted an opportunity by a renowned educator, cherished friend and valued mentor, Rabbi Alan Berkowitz, to work as the Director of Student Life at a school he was the Principal at in Brooklyn. He gave me the opportunity to involve the next generation of children with programs, events and speakers who were bettering the world each in their own way. While it was an opportunity to teach, I learned much from my students.

About three years ago, my friend of over 50 years, Alan T Brown had a phone conversation with Michal Ramon the CEO of **Access Israel** who invited him to come to Israel. Alan had not been in Israel in 30+ years and was concerned about accessibility as he is a person with paraplegia. Michal made it clear that Israel is accessible.

A few month later Alan was in Israel and texting, emailing, calling, and sending pictures of his trip and the places he was visiting. He then called while I had students in my office said, "We have to start an organization in the USA, and you are going to be the Executive Director".

That summer, I met Yuval Wagner, the founder of Access Israel and in the first minute I realized this is a man that I want to work with. With his angelic smile and focus on good – he was a person whose positive presence I desired in my life.


Yuval, and Jamie meet President Rivilin of Israel

I met the rest of the Access Israel family and simply fell in love with all of them, what they were doing and their grand vision of 'leaving no one behind'. The following Summer, during a moving ceremony celebrating the 20th Anniversary of Access Israel at the home Reuven Rivlin, President of the State of Israel, the President turned to Friends of Access Israel (FAISR) representative with a message of encouragement "Our friends from abroad, from the United States - Welcome! We appreciate very much what you are doing because this is a humanitarian need for everyone to respect human beings as a human being, not only as an Israeli or American, British, or Russian. We appreciate your collaboration and partnership".

What is the primary purpose of Friends of Access Israel and how does it help people with disabilities and their families? Our primary goals:

- Promote awareness of accessibility issues and of the inclusion of people with disabilities in North America and globally.
- Bring knowledge, methodology, and technologies using the award-winning Access Israel model, to the North America.
- Raise funds to promote accessibility and inclusion issues in Israel and elsewhere, encourage tourism to Israel, and other global bucket list items for people with disabilities.
- Collaborate with Access Israel on various other programs to accelerate accessibility for all.

To Table of Contents

As an example, we (non-Covid times) take pride in our awareness and sensitivity training as we see the fruits of the event instantaneously. One of the FAISR's awareness-raising activities is the Feast of the Senses, an experiential dinner that allows the participants to experience a meal through the eyes of people with disabilities. The meal simulates visual, hearing, and physical disabilities and creates a unique experience that changes the perception and understanding one had about people with disabilities. At the feast, participants go through an emotional and educational experience. They are served 3 courses; the first course is eaten while their eyes are covered, the second course while their hands are covered with special gloves and the third while their ears are covered to simulate the loss of the senses. During the meal, an open dialog is held with people with the specific disability which the participants experience.


Feast of the Senses

Access Israel and Friends of Access Israel have run these programs in the Israeli Parliament, in the UN Headquarters, for corporations, universities, day schools and in individual homes.

We are continuously building a global foundation to educate students, corporations, houses of worship etc. on the importance of inclusion and accessibility. We consciously taking this 'marathon', one mile at a time.

What are the biggest challenges facing Friends of Access Israel? Every state and every country views disability and accessibility rights and requirements in vastly different ways. Sadly, we still see countries that outright dismiss people with disabilities. Our ultimate goal is to have a set of global rules in place to set a minimum of requirements for all countries on accessibility.

Why was it important for you to be a voice for people with disabilities? I was blessed to grow up in a home with parents that taught by deed. They worked in stealth mode to be advocates for those in need in our community and beyond. My Dad a career United States Marine, instilled the idea that he 'never left a marine behind'. It was the lessons of my parents that set the foundation for me to attempt to fill part of their shoes.

Are there changes that still need to happen? Why? There is a lot that must change. The global view of the largest minority in the world must be a united one…. once we are close to that unity in accomplishing goals will be easier

How is the US different from other countries when it comes to accessibility and activities for people with disabilities? Should anything be different?
In the USA, the laws are in place. Following them should not be a matter of 'law and order' but rather an eagerness of organization, architectural firms, builders, etc. to make the world more inclusive and accessible as a standard.

Why is it important for the world to be more inclusive, to adopt a true concept of "Inclusion"?
In a nutshell, as we grow older and live longer the minority of people with disabilities is going to increase and the need for accessibility and awareness will be even more vital. We have an opportunity to set the bar high so that in the future will enhance the world for all.

With the recent announcement of the Abraham Accords last August, who should be at the table to discuss and share Best Practices for accessibility, inclusion, and equity for people with disabilities?
Peace is always very much welcome. In Hebrew, the word for peace, shalom is rooted in the word Shalem which has many meanings including full, complete, inclusive. A complete peace between entities is multi-level. The historic Abraham Accords brings with it the vital opportunity to share information so that all people are included and have full accessibility. The goal being that all can live self-determined lives enabling them to work, travel, study, and consume with dignity, equality, and maximum independence.

From the outset the people who should sit at the table to discuss this vital multi-national and multi-faceted information and best practices for accessibility, inclusion, and equality for people with disabilities should be recognized, respected leaders and informed people who represent and will get things done. In order for true shalom, peace to thrive it must be shalem, inclusive.

Who is your role model? Your inspiration? I am a firm believer in God. I believe He has placed all on this earth for a reason and has set guidelines for us especially on being there for our 'fellow sisters and brethren's keeper'. In striving to do good for others, it enhances His world with good.

Psychologically, as a person with PTSD going good keeps me focused on it and away from the evils that exist in the world. My parents, wife, and children remind me every day: with one good action - many more can come.

Anything else you would like the readers to know about you or Friends of Access Israel?
We are a non-denominational non-for-profit organization eager to work with other organizations, embassies, schools etc. to enhance the reach of our goals to globally improve accessibility and inclusion for people with disabilities and the elderly via advocacy, education, and inclusion. With each improvement we empower them to live self-determined lives enabling them to work, travel, study, and consume with dignity, equality, and maximum independence.

TO FIND OUT MORE ABOUT FRIENDS OF ACCESS ISRAEL

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Linkedin: faisr

Click here to DONATE to Friends of Access Israel

To Table of Contents

ACCESS ISRAEL'S TRIP TO MOUNT KILIMANJARO





Yosef Rubinoff

"Never Give Up!"



YOSEF RUBINOFF has proven that having a disability does not prevent you from realizing your dream. It may temporarily halt the dream's progress, but it is possible to rise after you have fallen, and most importantly, you should never, ever give up! Seventeen years ago, it was just another day for then 21-year-old Yosef, who was at the time serving in the artillery section of the Israeli army. Growing up Jerusalem, his was a normal childhood and, like many of the young people in Israel, he got drafted into the army. One day, he was assigned to carry shells weighing 50 kilos each – four shells per minute, during an exercise. He became aware of an uncomfortable sensation in his back – something did not feel right. He mentioned this to his supervisors but they did not take him seriously, thinking his complaints were just a ploy to get out of the task at hand.

Despite months of being in pain, Yosef pushed himself to continue his service, until one day during active duty he collapsed. Yosef was rushed to the doctor, who recommended immediate surgery, or run the risk of becoming paralyzed. There was no choice but to operate.

Yosef's injury at the age of 21 has resulted in his not being able to sit. He can only lie down. Four surgeries later - two in Israel and two in the United States have given him the ability to position himself at a 45-degree angle, walk short distances with the use of crutches, stand for very short periods of time, and also ride a Segway to get around, but the majority of his days are spent in a prone position. Back and leg pain have been his constant, unrelenting companions. Medicines have become ineffective, so he has resigned himself to living with pain.

But Yosef had a dream. That dream was to become an attorney and the pain he lived with every day, the unusual posture he was forced to maintain, the inability to navigate his way around the community in the accustomed vertical position society expects to see, was not a deterrent. He was prepared to fight for his right to be what he wanted to be, and fight he did!

After the injury which rendered him primarily horizontal, he was still able to swim and therefore worked part-time as a swimming instructor. However, he needed a permanent job, one that would allow him to be financially independent, provide for his family and give him the resources to pursue his dream of a law career. Finding employment, however, was extremely difficult. The general consensus from potential employers was, "if you can't sit, you can't work". His job search spanned a demoralizing 10-year period, during which time he faced subtle and overt discrimination. By law, businesses in Israel must employ a certain percentage of people with disabilities, but even if they complied with that law, Yosef's type of disability



was not welcome and excuses for not being able to employ him were constantly made. Throughout his painful, emotionally draining job-search, giving up was never an option, and Yosef's perseverance paid off. He eventually found employment with the electric company in Israel. This company looked beyond his disability, beyond the adjustments they had to make to his work space to accommodate his recliner and saw him first, as a person. He works there only part of the day, but through the open-mindedness of this inclusive employer, he has regained his dignity and proven that one must never give up.





With one of his battles overcome, Yosef now faced another: his dream of becoming a lawyer. "How can it be?", he was asked many times. "You cannot sit, or stand, you only lie down". No schools were willing to accept him and some were not subtle about this – they just said no! But he persisted. "No" was not an answer he was willing to accept. Eventually, one school said yes and he was allowed to attend classes lying on his bed. Some of the lecturers were understanding and kind, but most were not, and Yosef endured much during that time. He remembers one in particular who publicly chided him asking whether he was not embarrassed to be lying in a class on a bed in full view of everyone. True, the comment hurt, but Yosef pressed on.

After 3.5 years, he completed his law studies, but yet another hurdle stood in his way. In order to be admitted to the bar, he needed to complete a period of internship with a law firm but again, his disability proved to be a hindrance - none would accept him. The requirement was 1 year of internship working full time. They pounced on his inability to work for an entire 8-hour work day and said "sorry, we can't employ you". But Yosef countered with, "instead of completing the internship in one year, if I'm allowed to work part-time because of my disability, I guarantee I'll be able to complete the requirement in 1.5 years". The answer was still no. Yosef did not give up.

Through an organization that advocates for the rights of people with disabilities, he was eventually given the green light to work reduced hours to fulfill his internship requirement. Covid-19 has delayed the start of this job, but post-pandemic, he will embark on the next step of his legal journey.

Yosef's story is one of resilience and of the determination to succeed no matter what the odds. For years, he has been emotionally brave but admits he has experienced depression, especially recently. What bothers him the most is that he is not able to play soccer with his kids or run around and have fun with them. He believes that for years he was in denial about his disability and this allowed him to press on, relentlessly. Recently, however, the pressures of the constant fight for basic rights have been a sad reminder that he does have a disability and that not being accepted by society may always be a part of his life.

The feelings of helplessness are never allowed to germinate. Yosef thrusts them aside and forges ahead as he reflects on the many things in his life that provide joy and happiness. He has a beautiful, supportive wife and three lovely children, 10, 7 and 2 years old. He is able to drive, albeit standing at a 45-degree angle. He gets around on a Segway.

He participated in a half marathon while lying down on his hand bike. He recently embarked on a 2nd degree program - Managing Non-Profit Organizations. He just concluded a 4-week course that puts him in charge of accessibility for the electric company he works for. He found employment at a law firm where he will be able to complete his internship, post pandemic. He is also an author, having just completed his book detailing his journey. Written in Hebrew, it is called "Getting Up Again", and will be available on Amazon.

Although oftentimes beset with sad thoughts, Yosef's self-advocacy continues and he refuses to allow society's barriers to prevent the achievement of his dream. He is almost there. Soon he will be a practicing lawyer and vows to be a passionate advocate for others, using his legal training to help the vulnerable. He understands first-hand the limitations faced by people with disabilities and the subtly disguised discrimination they often face. He will be their voice. He is optimistic about his future.

Yosef hopes his story will inspire others and show that no matter what life sends your way and the barriers society may erect, you can find a way, you can achieve your dream. Whether you walk, stand, sit or lie down, you must never give up!





MARINA CLARKE
National Director,
Epilepsy South Africa

"The World Health Assembly (WHA) adopted Resolution 68.20 in 2015 creating worldwide focus on epilepsy. This led Epilepsy South Africa to establish a project to ensure implementation through the creation of a National Epilepsy Task Force to develop a National Epilepsy Plan.

The WHA decision to adopt Resolution 73.10 in November 2020 was a landmark event. Calling for the development of global action plans to combat epilepsy and neurological disorders was a first. The Resolution resulted from the sustained efforts by the International League Against Epilepsy (ILAE) and International Bureau for Epilepsy (IBE). Epilepsy South Africa is the South African Chapter of the IBE and thus supported these efforts."



Epilepsy South Africa

Overview of the organization

Epilepsy South Africa is the only national organisation in our country addressing the needs of persons with and affected by epilepsy.

The organisation was established in 1967 as the South African National Epilepsy League (SANEL) but changed our name to Epilepsy South Africa in 2002.

Epilepsy South Africa is a full Chapter of the International Bureau for Epilepsy (IBE) with strong ties to IBE Africa and the South African Disability Alliance (SADA).

Our organisation comprises a small virtual National Office with six Branches:

a) Epilepsy SA Western Cape based in Cape Town;

b) Epilepsy SA South Cape/Karoo based in Knysna;

c) Epilepsy SA Eastern Cape based in East London;

d) Epilepsy SA Gauteng based in Springs and Johannesburg;

e) Epilepsy SA Free State & North West based in Parys; and

f) Epilepsy SA Mpumalanga & Limpopo based in Dullstroom and Elandsdoorn.

We follow a human rights approach to our work and subscribe to the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) which was translated at national level to the White Paper on the Rights of Persons with Disabilities (WPRPD).

As such, advocacy and the development of self-representation is a key element of our work. Our services are largely psychosocial and include

a) Social development (e.g. counselling, residential care, community outreach and support groups);

b) Economic development (protective workshops, income generation projects, open labour market employment and entrepreneurial development);

c) Skills development (learnership, internships and short courses)

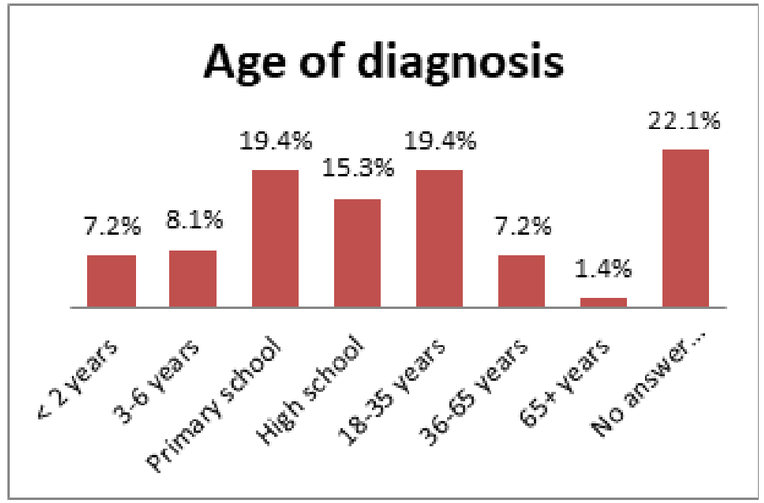
To Table of Contents



Percentage Of The South African Population With Epilepsy And The Age Range With The Highest Incidence

While some data exists about the prevalence of disability, there is a significant lack of data about epilepsy as this information is not captured by Government. As such, we base our assumptions on the statistics provided by the World Health Organisation (WHO) that one in every hundred people in a developing country like South Africa has epilepsy.

Through a survey we conducted in 2020 we established an apparent trend for epilepsy diagnoses in the younger population.



Epilepsy stigma

Persons with epilepsy are one of the most stigmatised groups in South Africa with several myths and misconceptions.

These include the well-known references to curses and magical spells as causes of epilepsy, but also extend to interesting suggestions for treatment such as pouring water over a person during a seizure or burning selected herbs to cure the person.

As an organisation we believe that awareness and knowledge about the condition are key elements to ensure acceptance and inclusion of persons with epilepsy. While we have several active social media campaigns, we also participate in media interviews and conduct awareness talks and workshops in communities.

Our key calendar event is International Epilepsy Day which is celebrated on the second Monday in February followed in South African by National Epilepsy Week. Other important events include Human Rights Day (24 March), SUDEP Action Day (23 October) and International Day of Persons with Disabilities (3 December). Our Advocacy Toolkit comprises brochures, posters, video clips and activity material and supports the outreach work of both staff members and self-advocates while our electronic library enables easy access to information about epilepsy.

South African Epilepsy myths

The most common myths and misconceptions about epilepsy include:

- Epilepsy is a sign of spiritual possession, a curse or magical activity. This means that persons with epilepsy may have special powers (e.g. foretelling the future).
- Because epilepsy is contagious contact with anybody who has epilepsy or a family member/friend with epilepsy must be avoided.
- Epilepsy affects intelligence which means that children with epilepsy cannot attend school nor can people with epilepsy learn skills such as driving.
- It is important to put something in the person's mouth during a seizure to prevent them from swallowing their tongue and dying.
- Seizures are always medical emergencies and you should call an ambulance immediately.
- There is only type of seizure – a convulsion.
- You can stop a seizure by lighting a flame and letting the person inhale the smoke. Other suggestions include pouring a bucket of water over the persons.
- People with epilepsy should be pitied, feared or ignored.
- People with epilepsy are lazy and an employment risk.

Management of Epilepsy

While there is no cure for epilepsy the condition can be effectively treated. The objective of any treatment is to control seizures with the least side effects.
Effective treatment requires a proper diagnosis by a medical practitioner (ideally a neurologist). Diagnosis is based on an accurate medical history (usually provided by both the individual and family members) and one or more tests (e.g. EEG or MRI scans).

The most common treatment for epilepsy is anti-seizure medication. Unfortunately, such medication may have unpleasant side effects and requires adjustment over a period of time to find the most suitable drugs and dosage for the individual. As a result, some people with epilepsy feel that the treatment is not working or unpleasant and opt to stop taking the medication. Any changes in treatment must be discussed with your doctor.

A medical investigation will determine whether persons with epilepsy are suitable candidates for other forms of treatment, e.g. surgery, the ketogenic diet or Vagus Nerve Stimulation (VNS).

While the need for medical treatment is obvious, persons with epilepsy are ultimately responsible for managing their condition. This not only requires adherence to treatment (e.g. taking medication as prescribed), but also through lifestyle management as this supports the medical treatment and contributes to overall wellness.

Lifestyle management includes a healthy diet, regular exercise, good sleeping habits and stress management. It is important that persons with epilepsy identify their individual seizure triggers and take action to avoid or limit exposure to these. Keeping a seizure diary is helpful in identifying triggers which vary greatly from person to person. Triggers may include weather (e.g. high/low temperatures), specific foods (e.g. caffeine or sugar), alcohol and recreational drugs, flickering lights (applicable only to persons with photosensitive epilepsy), smells, hormonal changes (e.g. menstrual cycles and menopause) and many others.

By keeping a seizure diary you will record what happened before, during and after a seizure which will help you to identify potential seizures. Epilepsy South Africa offers a free seizure diary which can be

downloaded from the Epilepsy Information section of our website (www.epilepsy.org.za).

Can epilepsy be prevented?

It is impossible to determine the cause of epilepsy in approximately three quarters of cases. As such, it is not always possible to prevent epilepsy. However, some key causes of epilepsy include illness (e.g. meningitis or encephalitis), head trauma (especially cerebral haemorrhage), drug and alcohol abuse, tumours, biochemical imbalances and degeneration (i.e. ageing).

Preventative measures include:

- Taking precautions to avoid head trauma (e.g. wearing a seat belt in vehicles and protective equipment when playing sport);
- Regular medical assessments to ensure early detection of high-risk conditions; and
- Responsible behaviour (e.g. limiting alcohol intake).

COVID-19

The redirection of available funding to Covid-19 interventions and delays in processing previously agreed funds reduced the available funding for the work of Epilepsy South Africa. In addition, the economic hardships resulting from strict lockdown protocols resulted in individuals no longer able to support our work financially. Organisational income generation activities (e.g. retail and service provision) were also curtailed.

These factors combined to place significant strain on the financial wellbeing of the organisation as a whole.

Our service delivery was negatively impacted by prescribed lockdown protocols which limited interaction between people. As such, our community outreach came to a virtual standstill with support only available telephonically or online. Support groups could obviously not meet and virtual meetings proved challenging given the high cost of data in South Africa and the lack of access to technology.

Persons employed in our protective workshop were not able to work which reduced their income significantly. Emergency relief support proved to be ineffective and inaccessible to many.

However, the pandemic and accompanying lockdown also helped our organisation to find creative new ways such as hosting virtual meetings with a significant reduction in costs.

Access to care and employment for people with epilepsy

Global economic trends have a significant impact on the South African economy as evidenced by less than 2% growth in recent years. The impact is evidenced by increasing unemployment (particularly amongst young people), cutbacks in and redirection of government spending and a significant reduction in funding for social issues. National and international trends impact the opportunities available to persons with and affected by epilepsy and thus access to care and employment.

While Epilepsy South Africa offers limited residential care, we believe in the inclusion of persons with epilepsy in communities, preservation of the family unit and independence. As such, admission to residential facilities is limited to persons requiring a high level of care due to their epilepsy and comorbidities/disabilities, as well as the ability of family members to provide the required levels of care. We thus offer support to families and communities to enable persons with epilepsy to actively participate in their communities. In addition to counselling services we also assist with access to social security and services at local level.

In terms of employment Epilepsy South Africa focuses on placement in the open labour market and protective employment, as well as self-employment and entrepreneurship. However, the stigma surrounding epilepsy can be seen in the unwillingness of many persons with epilepsy to disclose their condition despite employment equity legislation.



16 Days of Activism

However, the high unemployment rate in South Africa (currently estimated at 30%) means that most persons with epilepsy remain unemployed and reliant on limited social security, their families and communities.

The legacy of South Africa's past continues to plague persons with epilepsy given poor education and skill levels. This means that many people do not have the required skills and experience to effectively engage with market requirements. In response, Epilepsy South Africa established skills development services in partnership with government agencies and the private sector with a view to improving the employability of persons with epilepsy.


Mascot, *Flame.*

www.epilepsy.org.za

FONHARE

Fondation Haïtienne de Réhabilitation

Haiti



FONHARE is a well known humanitarian organization working in Haiti since 2011 in the fields of: Health & Rehabilitation, handicap prevention and maternal-child-health, inclusion, universal accessibility, socio-economic reintegration of vulnerable groups, combating gender based violence, promoting child protection and Inclusive Disaster Risk Reduction.

Over the years, FONHARE has accumulated national and international recognition. Every month, more than 2,000 people benefit from FONHARE's services in Ouanaminthe, northeast region of Haiti, but in September 2021 FONHARE will no longer have a place in which to operate and all these services will disappear.

To avoid this collapse, board members, friends and the community have come together to finacially support the construction of FONHARE's own building which started on December 14, 2020. They worked hard and fast on it with paid and volunteer staff and have now arrived at the last phase, the roof. They have raised and spent $40,000 USD so far. They still need about $70,000 USD to complete the construction which is a massive challenge but they are hopeful to raise the required amount before September 2021.

To Table of Contents

Donations are welcomed. Donor's names will be placed at a strategic corner of honor in the building.

For learn more about FONHARE's work in Haiti:
Website: www.fonhare.org







To Table of Contents

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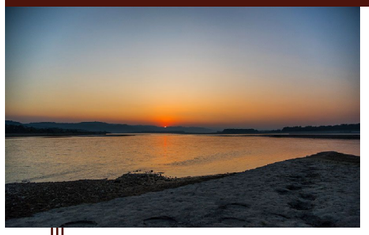







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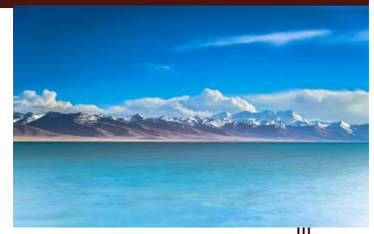



Bhutan









Myanmar





To Table of Contents

RESOURCES

FOR PEOPLE WITH DISABILITIES

ACCESSIBILITY CONSULTANTS

FJM Solutions, *USA*

Massiraa, *Dubai*

Marco Pasqua, *Canada*

BUSINESSES OWNED BY PEOPLE WITH DISABILITIES

Collettey's Cookies, *USA*

CERTIFICATION COURSES

Rick Hansen Foundation Accessibility Certification, *Canada*

DISABILITY-SERVING ORGANIZATIONS

Access Israel, *Israel*

Easter Seals, *Canada*

Easterseals, *USA*

FONHARE, *Haiti*

Friends of Access Israel, *USA*

The American Association of People with Disabilities, *USA*

EMPLOYMENT

Bender Consulting, *USA*

HOSPITALITY TRAINING

The Slatin Group, *USA*

INCLUSIVE EMPLOYERS

Gabi & Jules, *Canada*

Lil E Coffee Cafe, *Canada*

LEARNING CENTRES

Achievement Learning Centre, *Dominica*

MEDIA

Accessible Media Inc., *Canada*

OUTDOOR ACTIVITIES

Paratrek, *Israel*

PRODUCTS & ACCESSORIES

Izzy Wheels, *Ireland*

TRAVEL

360Access, *USA*

AccessNow, *Canada*

Accessible Indonesia, *Indonesia*

Japan Accessible Tourism Center, *Japan*

European Network for Accessible Tourism (ENAT), *Belgium*

Four Season Travel & Tours, *Nepal*

Travel-for-All, *Canada*

WEB ACCESSIBILITY

EqualWeb, *Israel*

CLOTHING

Intimately, *USA*

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