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Editorial pages have VOICEYE codes for a new level of content access - *Enjoy*

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MANAGING EDITOR
Gillian Friedman, MD

MANAGING HEALTH EDITOR
E. Thomas Chappell, MD

CONTRIBUTING SENATOR
US Sen. Tom Harkin (D-IA)

HUMOR WRITERS
Jeff Charlebois
George Covington, JD
Gene Feldman, JD

EDITORS
Don Armstrong
Ming Canaday - Translation
Paula Fitzgerald
Renne Gardner
Christopher J.B.
Pamela K. Johnson
Lia Limón Martirosyan
Molly McGovern
Josh Pate, PhD
Maya Sabatello, PhD, JD
Romney Snyder

HEALTH EDITORS
Moses deGraft-Johnson, MD
Larry Goldstein, MD

CONTRIBUTING WRITERS
George Covington
Ashley Fiolek
Geri Jewell
Regina Hall
Myles Mellor - Crossword Puzzle
Paula Pearlman, JD
Allen Rucker
Betsy Valnes
John Williams
David S. Zimmerman
Danielle Zurovick, PhD

WEB EDITORS
Jason Kyles
Marge Plasmier
Mary Shafizadeh

MULTI-MEDIA
Helki Frantzen
Stanya Kahn

GRAPHIC ART/ ILLUSTRATION
Scott Johnson
Melissa Murphy - Medical Illustration

PHOTOGRAPHY
Nancy Villere— CrushPhotoStudios.com
Jennifer Esposito

TRANSCRIPTIONIST
Sandy Grabowski

MARKETING/PROMOTIONS
Joyce Parkinson
Marge Plasmier
Lia Limón Martirosyan

ABILITYJOBS.COM
Marge Plasmier
Casey Mims

EDITORIAL
editorial@abilitymagazine.com

PUBLISHER/EDITOR-IN-CHIEF
Chet Cooper

The views expressed in this issue may not be those of *ABILITY Magazine*

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FULFILLING THE PROMISE OF COMMUNITY LIVING

Dear *ABILITY* readers,

At a recent roundtable of the Senate HELP Committee, Emmanuel Smith described the challenges he faced growing up in Iowa with brittle bone disease. All his life, he feared that if he were to incur an injury, it would limit his independence and force him into a nursing home.

The freedom to choose home- and community-based services as an alternative to nursing homes and other institutional settings is critically important for Emmanuel and millions of Americans who live with disabilities. Thanks to the Supreme Court's ruling in Olmstead 15 years ago, full integration in society—a central tenet of the Americans with Disabilities Act (ADA)—was resoundingly reaffirmed.

With the passage of the ADA 24 years ago, and the Olmstead decision, which followed less than a decade later, our responsibility to people with disabilities is clear: We must ensure that they are provided with the choice to live in their own communities, and get the necessary support to do so.

When Congress passed the ADA, we described the segregation of people with disabilities as a serious and pervasive form of discrimination. In fact, the ADA clearly states that no person with a disability "shall, on the basis of disability, be excluded from participation in, or be denied the benefits of, the services, programs, or activities of a public entity, or be subjected to discrimination by any public entity."

One of the most important aspects of the ADA is the "integration mandate." In Olmstead, the Court ruled that the unnecessary segregation of individuals with disabilities in institutions was a violation of that mandate. Simply put, preventing people with disabilities from living in the community constituted discrimination and a violation of civil rights. Indeed, the Court wrote that such segregation not only isolates people with disabilities, it also "perpetuates unwarranted assumptions that [they] are incapable or unworthy of participating in community life."

Study after study has shown that home- and community-based care are not only what people want, but also are more cost-effective. Problems remain, however, despite the Olmstead decision. An investigative report that I released last year showed that more than 75 percent of states spend a majority of their long-term care dollars on institutional care and support, while more than 200,000 Americans with disabilities under the age of 65 remain unfairly segregated in nursing homes.

To guarantee that states are doing their part to fulfill the promises of the ADA and of Olmstead, I recently introduced the Community Integration Act. My bill will ensure that people with disabilities can choose to live in the community and receive the same supports and services under Medicaid that they would get in conventional institutional settings.

My proposal also holds states accountable by ensuring that they make available home- and community-based services for individuals with disabilities, while prohibits states from making anyone ineligible for such care. Individuals should be able to make a choice about where their long-term supports and services are available, something that my bill makes a reality.

One of the most powerful stories I heard at the recent

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roundtable was from Donna and Ricardo Thornton. They lived in an institution until their early 20s, had little individual control over their lives, and were isolated from their families. Despite having been in the same institution for over 20 years, they never met each other. Once they were able to leave the institution, they met, married, found jobs, and are now active community members. And they also became proud parents and grandparents.

The Community Integration Act will ensure that individuals with disabilities are given the opportunity to receive their services and supports in a community-based setting, where they can work, participate in community life, and play an active role in their communities.

Almost a quarter century since the ADA was passed, and 15 years after the Olmstead decision, it's time to ensure that the integration for all people with disabilities is promise that we keep.

ada.gov
ada.gov/olmstead
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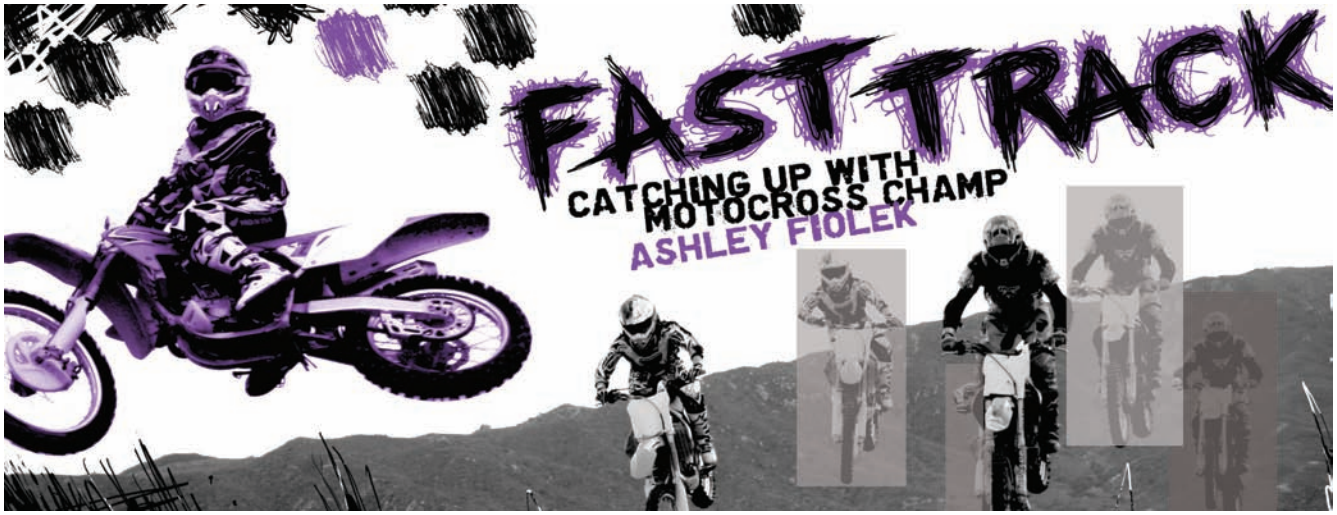
Sincerely,

Senator Tom Harkin

Senator Tom Harkin (D-IA) is Chairman of the Senate Health, Education, Labor and Pensions Committee

harkin.senate.gov





Since April I have been involved in a top-secret project, but now I can finally talk about it. A couple of years ago I received an award from a woman's stunt show group for my Red Bull commercial. To pick up the trophy, I went out to California, attended one of their stunt workshops, and got a chance to meet some really cool women!

Last year, someone from that event contacted me, and told me that Feld Entertainment was looking for some "stunt" women to ride dirt bikes for a new traveling show they were putting together.

My good friend, Brittany, who also rides, contacted the person who was looking for riders to get more information, like how many people they were looking for and what kinds of skills they needed for the show. Since we are racers and not really stunt women, we wanted to see what everything was about before we said "yes."

The contact person explained to us that it was going to be a traveling show based on Marvel comic books, and that they were looking for girls to be part of the villain group to ride dirt bikes and do fight scenes.

We told them that we were interested and to keep us posted as things developed. They told us that because it was such a big show, we would probably have to audition for it. Brittany and I were in Florida visiting my family and hanging out when the Feld/Marvel group contacted us again and asked us to meet up with them in Orlando for a fight-scene audition.

Before we flew back to California, they chose a place for us to audition near the Orlando airport. I was so nervous! We knew how to ride, but we certainly didn't know how to ride and fight at the same time. They showed us some basic moves. From there, we had to act them out. One time I fell so hard I wanted to scream, but I acted like nothing was wrong, which is kind of like racing! We had to jump from the top of a warehouse, 30-feet up, onto an air-mattress pit, which was nerve wracking, too! But when we finished, they said we did really well, and that we would hear from someone soon.

So we went back home and waited for their call.

After a month or so, they contacted us and asked us to be part of the group. It was great to be asked, but I wasn't sure I really wanted to do it. I had to commit for a whole year, which involved training, traveling and being away from home, friends and family!

Finally, I decided that this was a fresh new direction, and I should go for it. I would get to ride and travel the US, two things I love to do! I closed up my house and went back to Florida to train for this new adventure.

When I arrived in Florida, I realized that there were other racers who were going to be involved in the show. Some of the young women that I've know for a while and raced with were there, so it was a relief to know I wasn't going to be in it alone.

So far we have been practicing several months, and it's been pretty intense. The good part is that the show is now opening. Everyone is so excited because we've all worked very hard.

Marvel Universe Live is an ambitious show involving Marvel comic book characters. It has a storyline that includes tons of car crashes, motorcycle stunts, fires breaking out here and there. In short, it has it all.

I hope everyone will love the show and I'm really excited to be a part of it! If you check out the website, you can find out when a show will be coming to your area. Come say "hi" to me after the show. I would love that!

■ ABILITY

marveluniverselive.com
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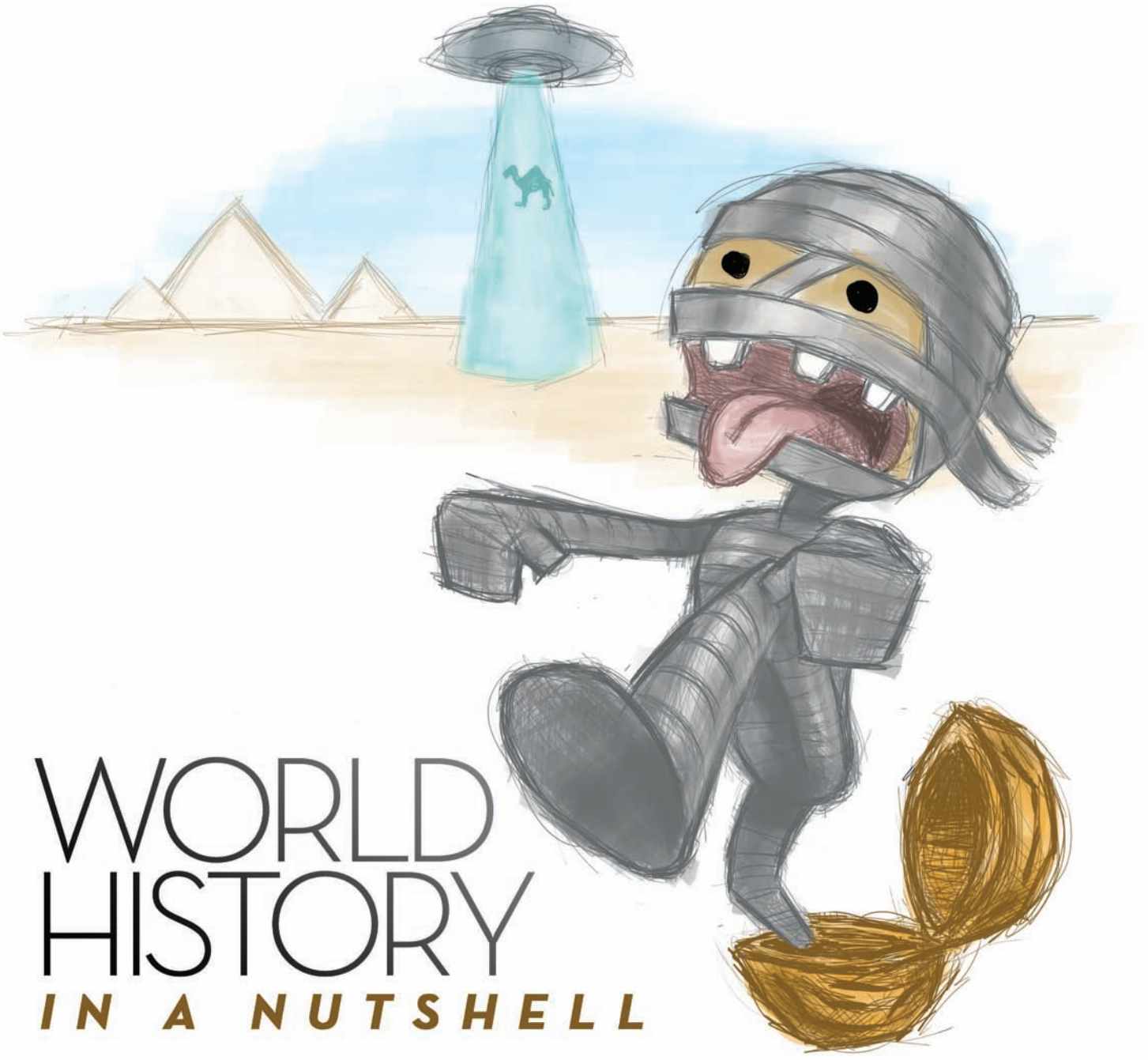
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WORLD HISTORY IN A NUTSHELL

The Egyptians were one of the first great civilizations to arise along the Nile River. These tanned people wore diaper-like outfits and drove around in compact chariots. Their big claim to fame was constructing giant pyramids so they could store dead pharaohs wrapped from head-to-toe in adhesive tape.

They must have been extremely big rulers because their tombs were humongous. Nobody knows how they were built. Many believe aliens were behind them. My thinking is that it was a highly advanced group of people in spaceships traveling at the speed of light could build a structure made of rocks, come on, what about plastic or fiberglass. It doesn't even have automatic doors to get in or how about duct tape for the mummies?
They also came up with something called hieroglyphics: symbols and stick men in suggestive positions, but hey, you've got to do what you've got to do to get kids to read. They found scribbling on hard surfaces was too time consuming so they invented papyrus and thus the first uh hem, hot images, were set down on paper. Forget how the pyramids might have been built, the bigger mystery was how the human body could contort into some of those positions.

For labor they used slaves, like the Jews, to build these monstrous monuments that took years to construct. The Jews were like, "We're tired of lifting big blocks and making large triangles." They thought it was all one big pyramid scheme, but their whining had no effect on the pharaoh, so they said, "Oy vay, we're out of here."
The pharaoh was like, "Oh no you ain't."

Moses stepped up and said, "You gots to let my people go."

"I ain't gots to do nothing," the pharaoh snapped back.

With God in Moses' corner, the big guy threw down a number of plagues on the Egyptians. There was a famine, scores of swarming bugs, and a bloody Nile to name a few.

Ra, the sun god, was no help to the pharaoh so finally he succumbed. "Okay, I've had it," the pharaoh barked. "I want all you crazy Jews out of here… and take your God with you, because I'm so sick of sleeping with frogs in my bed and picking festering boils on my skin."

That sounded good to the Jews so they fled north to a promised land, taking a shortcut through the Red Sea. They brought everything they could with them; food, tents, silver, goats, a golden calf, etc. The one thing they forgot was a map. Eventually, after forty years, they found a little plot of dessert land with high hopes of just living there in peace and quiet. Location, location, location. If the Jews knew what they were in for, they might've stayed in Egypt building pyramids. The pharaoh was left to cuddle with the Sphinx.

On the other side of them was a growing empire known as Babylonia, where the people spoke in incoherent sentences. It is thought that all foreign languages came out of there. The poor drank beer and the rich consumed wine, which may explain all the babbling. They invented the potter's wheel most likely to hold their booze. They also invented the seed plow which really pissed the oxen off. They were responsible for the first system of writing, and the earliest known codes of law.

These two elements paved the way for "the attorney." This prompted them to go grab the Jews and enslave them because they made the best lawyers. So, in 587 BCE, Babylonian Nebuchadnezzar's army captured Jerusalem, destroyed the Temple, and exiled the Jews to Babylon (modern day Iraq). Once again, the Jewish people were on the move.

At some point, the Persians rose to power under Cyrus who developed a unique form of governing. Everyone conquered could keep their language and culture, but not their money. Taxes went to maintain the exquisite gardens, which they trimmed into animal shapes. They would sit under fig trees and work on Algebra problems because they like to do math for fun.

They passed this knowledge onto the Jews, many of whom became shrewd accountants. Ultimately, Cyrus found the Babylonians annoying so he crushed their kingdom. The Jews exhausted him with their constant complaining about psychosomatic illnesses so he released them because the elderly women often made him feel guilty.

After arriving in Jerusalem, the Hebrews rebuilt their city and visited the temple to thank God that all their troubles were behind them. If they only knew. For now, things were looking up for the Jews. From Cyrus to Darius to Xerxes, these Persian rulers amassed a vast kingdom. Eventually, their greed for more power would be their downfall as they attempted to expand their territory into Greece. It was a no brainer because the Greek girls were virgins with a dowry.

In the Mediterranean, a teenage boy known as Alexander strolled onto the scene. He was taught by the famous philosopher Aristotle, and pondered questions like "Why haven't I taken over the world yet?" Up to now, the 19 year-old was only known by Alexander the So-So, but soon the hairy warrior would begin a snatch-and-grab mission in the civilized frontier.

He started out by uniting the Greek city-states and led the Corinthian League. It wasn't enough. The type A go-getter began to excel by becoming the king of Persia, Babylon and Asia, and created Macedonian colonies in Iran. It was quite an impressive résumé for such a young man who also liked to redecorate the empires he conquered. He changed his last name from "the So-So" to "the Great," which had a better ring to it. Malaria struck him in 323 BC and Alexander learned he couldn't conquer death.

Athens had developed into a hub with hang out areas such as the Acropolis and the Temple. Renowned philosophers like Socrates postulated, "To be is to do" while Plato formulated "To do is to be." Later Sinatra chimed in with "To do be do be do." Aristotle just wanted to know, "Who's your daddy?" These life teachers were respected and just wanted to know why. Was that too much to ask? Today, they would be considered unemployed bums with a worthless major.

On the other side of Greece, the city of Sparta was on the rise. It was known for its elite fighting force, which wore skimpy outfits. The soldiers were called hoplites because they could quickly hop around with their shields and spears. Soon Athens and its empire and the league led by Sparta would butt helmets and wrestle in the Peloponnesian war. This would bring about marathons and Olympics.

They had gods for everything and plays were written about them. The characters lived in oceans, caves, mountains and the depths of hell, to name a few locales. There were gods of love, music, war, pleasure, drunkenness, etc. Those Greeks had a lot of breadth. This god crew did silly things like go on Odysseys, fight one-eyed monsters, kill siblings, sleep with their mothers and even turned people to stone. These gods were so confident that they refused to wear clothing when being sculpted. One thing is for sure, no one ever asked the Venus di Milo to ever lend a hand.

Off in the Far East, the Chinese were busy building a great wall in hopes of keeping invaders or pesky rodents out of their country. Dynasties from the Shang to the

Ming to the Qing would rule. Many traveled by horseback but for some reason were very poor drivers. Chinese restaurants were popping up everywhere and egg rolls were the rage. Kingdoms soon began warring because people were upset about the nonspecific lame fortunes in their cookies. The emperor was the only one who ever won. Monks began fighting each other with kung fu, swords and chopsticks. At some point, gun powder was invented and soon firework stands were popping up all over the countryside.

To the west, in the boot shape territory known as Rome was a republic supposedly created by the offspring of a She-wolf. As the people began to pull together as a community they elected several kings which morphed into a senate body which then granted Mr. Gaius Octavius the "Augustus" title—which meant "divine." It affirmed his position as the most important man in the empire and brought an end to the Roman Republic. With a new emperor, a new empire could rise and let the orgies begin.

Julius Caesar climbed the corporate ladder from infamous general to the Godfather of all Rome. As their leader he would conquer more land, invent a salad and get busy with Cleopatra, who would later get busier with Caesar's best friend Marc Anthony. "When in Rome…"

The Roman Empire reached from Europe to Africa to the Middle East, then reached in everyone's pockets. Sometime in the first century, over in Israel, the son of God raised a ruckus by healing people and teaching folks how to love one another. Some didn't like that message so they decided to teach their own philosophy of hating and crucified Him. The love your neighbor thing finally did catch on and began to resonate and this new Christianity began to spread all over the world.

Everyone had their own ideas of how this religion should be run, so someone had to be in charge of the flock and thus the pope became the new emperor. The pontiffs of ancient times helped in the spread of Christianity and the resolution of various doctrinal disputes. It was their way or the highway. The highway to hell that is. Major decisions like being forgiven, going to heaven and how much money you need to give to the church would now rest in his holy hands.

Over the years, Rome began to weaken and was splitting into two empires. In 455, the barbarians, namely the Vandals sacked the city. It was like Revenge of the Nerds. The Germanic tribe looted what they could snatching things like grain, pottery, candles, togas and lots of wine barrels, after all, it's not a party without the booze. The Romans were like "What the hell happened to the good life of decadence and debauchery?" The senator bribes would stop, the orgies would seize and the pope got the hell out of Dodge and moved to Byzantium while the Jewish people would be scattered around the world. In the other hemisphere, the Aztecs in Central America were eating chocolate Acai berries and ripping out hearts to appease their Sun God. The North American Indians were enjoying life—hunting buffalo, smoking peyote and tickling each other with eagle feathers.

The Byzantium Empire started to flourish as Europe was coming into the light while still in The Dark Ages. The economy was among the most advanced in that whole neck of the woods for many centuries. The main city, Constantinople was a prime hub in a trading network that at various times extended across nearly all of Eurasia and North Africa. It was the main stop on the Silk Road which would later became Route 66. They gave us mosaics, palaces, monasteries and probably area rugs. The Muslims and Turks would often attack them because they were stealing all their mathematics and astronomy knowledge and making claims like they invented the Pythagorean Theorem and discovered not only the Big Dipper but the little one as well. The Byzantines were a smorgasbord of people that spoke Greek, Arabic, Latin and maybe even some Pig Latin. They would flourish for over 1,000 years.

The authority of the Byzantine emperor as the legitimate Roman emperor was challenged by the coronation of Charlemagne in the year 800. He was crowned the new emperor by Pope Leo and thus began the Middle Ages, which began at the start and not the middle. This king basically united most of Europe, converting them to Christianity with mottos like, "You either love our God of love or we'll kill you." Hey, whatever works. This attitude spilled over to the crusaders in the tenth century. The crusaders, who used Constantinople as a rest stop, had a mission to free the Jews from Muslim control and gain access to the holy sites in Jerusalem and to prevent the expansion of Islam to the near east. At times, they killed some Jews obviously forgetting their goal of freeing the Jews.

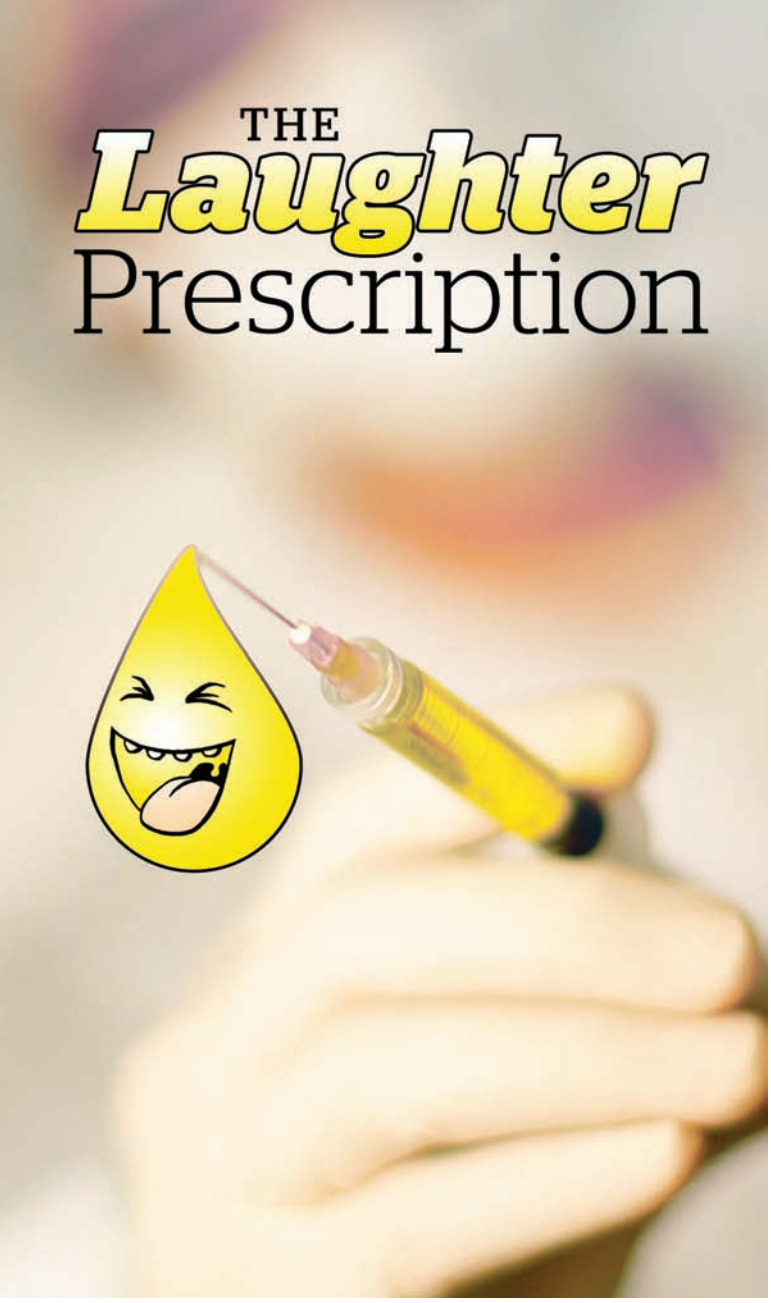
Things reached a grinding halt in Europe when the Black Death emerged. This disease really plagued the people. It was carried by fleas on the bodies of rats… and that's fur real. It was a valuable lesson in always brushing your rat before snuggling in bed with it. The Bubonic Plague wiped out over 100 million people. On an up note, it really opened up the job market. You could not warn people of the dangerous epidemic by tweeting either, simply because no one could read. Because of the devastating disease, people reawakened to their own immortality and got in touch with their humanistic spiritual side and their world view began to change. The renaissance was about to blossom. Can you say naked paintings? We'll delve more into that in part two. ■ ABILITY



by Jeff Charlebois

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THE Laughter Prescription



Has a doctor ever given you a prescription for laughter? No? Too bad, because laughter may very well be the most non-toxic, life-altering drug we can get! It doesn't matter what's ailing us, whether it be cancer, diabetes, cerebral palsy, high blood pressure, or arthritis—laughter can help all those conditions. Not to mention other things that may threaten our well being, such as unemployment, grief, traffic jams, and the tremendous confusion and stress of trying to wrap our brains around the Affordable Healthcare Act and other insurance matters.

The good news is that no matter what insurance policy you have, or what your deductible is, laughter is free! Yup, it's free, and if your doctor will not write you a prescription for it, then write your own. If you have to have a visual, then take an empty pill bottle, put a "laughter" label on it, and fill it with sugar-free candy. Every time you take a laughter pill, you must laugh for 10 minutes! Dosages may vary, but I personally recommend at least three "pills" a day.

Why? Because it will make you feel better, and that good feeling is highly contagious, so you'll help others feel better too! Laugh with your family, friends, colleagues and doctors. If this is not possible, then laugh all by yourself. You might even consider laughing with strangers. However, I do caution that your laughter be in good fun, no cruel jokes at someone else's expense. That will only prolong whatever ails you in the first place.

It might also surprise you that you don't even have to have a sense of humor to laugh, although it certainly helps. Laughter is a powerful healing tonic physiologically. The brain does not know the difference between a real laugh and a phony one—unlike a fake orgasm. When we laugh, the brain releases endorphins that ease the stress and pain we're dealing with. Truthfully, if I personally did not have a sense of humor, I would have given up a long time ago.

Recently I had to meet with a social worker about the daunting subject of health insurance and disability: HMOs, PPOs, who's covered, who's not, and what I needed to do to qualify. I was so overwhelmed that I was on the verge of tears, when all of the sudden I smiled and said, "Do you think Helen Keller had to deal with all this @*#&?" I laughed, the social worker laughed, and we both enjoyed the momentary comic relief and felt a tad healthier for it.

Bear in mind that the language of laughter is universal. Yes, we may not all laugh at the same things, but if anyone were to play a CD with only the sound of laughter on it, we would all "get it," find ourselves tickled, and join in.

When I was a kid, my whole family would often start laughing at the dinner table, and usually it was my older brother, Fred, who started it. If it was a particularly intense atmosphere—maybe my sister, Gloria, being forced to finish eating something she hated, or my dad being in a foul mood for no other reason than that fact that he was in a foul mood—Fred would cut through the tension by making faces when dad wasn't looking. Or he might take food off Gloria's plate in plain sight, and "hide" it under her plate. Even my dad could not help but laugh. It changed the energy at the table, and suddenly we were all giggling and enjoying one another's company.

Remember the line from the movie, *Forrest Gump*, "Stupid is as stupid does?" Well consider this: Funny is as funny does! And yes, funny does a lot of things—mainly give us a break from all the frickin' drama that can bombard us from all directions, blocking our innate childlike nature that delights in having fun. So don't forget to take your laughter medication three times a day and LOL. ■ ABILITY

by Geri Jewell

gerijewell.com





Voice Box

I was born with a speech impediment. Ideas flourish in my mind, but they just don't transfer smoothly through my vocal chords like other people. Having this stuttering disability subjected me to a cloud of hopelessness for a large portion of my life. I thought my dreams would never come to fruition, that I could never feel normal or accepted. Sure, public speaking is a common fear, but I could not even speak privately; in fact, for the longest time, I did not believe I had a voice.

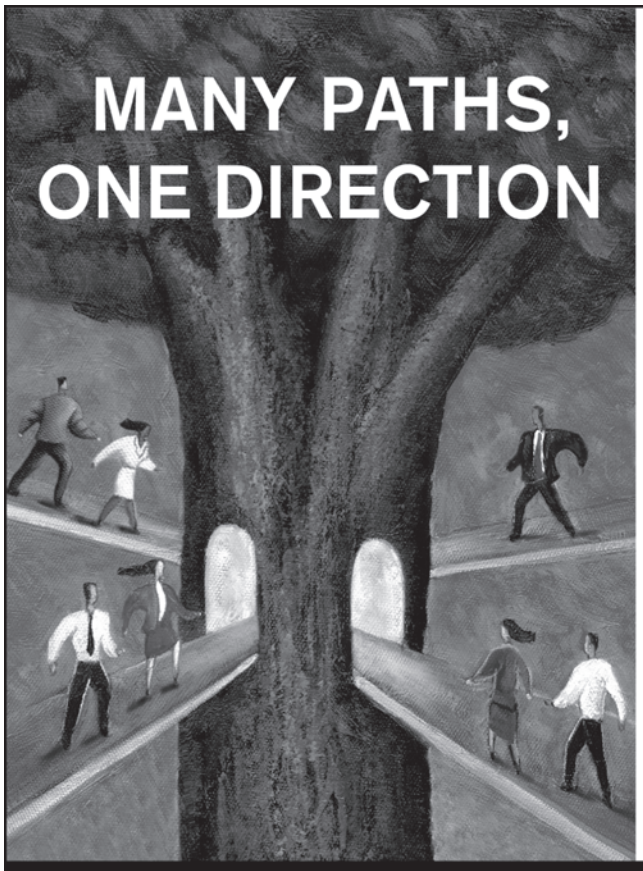
As far back as I can remember, I have stuttered, and expressing myself has never come as simply as it does for most people. Stuttering is developed in the voice box with something like a clasp cutting off air through the valves. I never know when a block might occur, but it feels like a damaged, teetering building about to collapse in my throat. When it comes crashing down, my body is programmed to react rashly, ranging from shutting my eyes, flailing my arms and shaking my head, to making foreign sounds and other irregular body movements. It feels like you are drowning in a lake. You can do outrageous things to try and save yourself, but I need to do outrageous things simply to keep the meaning of one sentence audible. If I am unsuccessful in breaking through, I drown: lose the essence of my sentence. When this happens I am forced to go through the whole fiasco again, while also managing the side glares and stares: the unwanted attention stuttering grants. I have always felt trapped because something so damn basic for most people is always an uphill battle for me.

Making the transition to the real world was no different. I was terrified I would fall behind and not live up to society's standards. Throughout the first weeks I was looking for an internship, the pressure weighed on me. My stutter and my fear of public speaking were still ruling my life.

One of my first interviews for a technical internship was at a huge software corporation. I asked the hiring manager if we could conduct the technical interview over Google Chats since phone calls have never worked well for me. He agreed. Forty-five minutes into the virtual interview, I had nailed every question, from object-oriented programming to brain teasers to solving algorithms, I knew my stuff. He displayed his approval with a smiley-face emoticon every time I finished answering a question! At the end of the interview, he said I was "overqualified" and "would make an outstanding addition to his team." However, he wanted to do a quick phone interview right then, right now...

Immediately, my body was filled with the same debilitating fear that use to overtake me when my teacher would purposefully call on me in front of the entire class. While repressing my anguish, I agreed to the call in hopes that I would be able to do it. Finally overcome my impediment. I answered the phone at 12:06, the conversation was over at 12:08. "We feel like your language barrier would not be a good fit for our team. Thank you for your time, and please keep yourself updated on our career page." CLICK

Grasping for air and wiping my sweaty forehead, a rush of affirmation for all those who scorned me almost knocked me off my chair and into a sea of tears. There are few moments darker than the moment you realize you have been living a lie your entire life. After telling myself over and over I could do anything despite my stutter, the bitter truth shattered my hopeful illusion. I am nothing but a stutter, a disability, a detriment.



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DIVERSITY CREATES ENDLESS OPPORTUNITIES

From my lowest point in life, hopeless and defeated, I began studying the world around me, especially those with hardships. What I saw was that, from the kid who grew up in poverty, to the kid in the suburbs, to the special Olympics athlete winning a gold medal, to the star basketball player, and even to the people who seem to have it all, every person has a battle, a lifelong struggle. Understanding this truth revealed to me the fact that what defines us as people is not our struggles but our ability to overcome them.

When people define Dr. Martin Luther King, it is not by the humiliation he faced or the oppression he suffered but by his victory against the hatred that dominated his life. President Franklin Roosevelt is not characterized by the paralysis he developed after contracting polio, but his ability to overcome it in order to lead a nation.

Through this understanding, my stutter, which was once a source of anguish and imprisonment, transformed into the very fuel needed to jumpstart my stagnant life. I became more motivated than ever to show that my stutter does not control me, that I am great, and that, most importantly, I can do great things for other people. For months I set about refining my interviewing techniques through rigorous practice and reading. I built a brand around my disability that showed employers how it empowers me to do great things and unlocks valuable skills. No longer was I the detriment whose "language barrier" would not fit on teams, I became the engineer whose stutter created unique perceptive abilities, first-class problem solving capabilities, unmatched grit and an unstoppable motivation to overcome. I ended the hiring season with seven different internship offers from the top technology intuitions in Silicon Valley and endless future opportunities.

This small victory in my life will not be my defining moment. It has set me on a path to overcome the impossible in order to be defined by what I chose and not by my disability. I understand it is not easy to deviate from your own routines, your norms, your history, just as it was hard for me to break out of mine. But understand that we are defined by our ability to do the impossible. So if you are willing to fight, nothing can stop you. Stuttering has taught me compassion, understanding and resilience. My voice is real and my voice is strong. From emotional imprisonment to newfound empowerment, I've discovered my passion, and I owe it to my very own agent of change. My stutter. ■ ABILITY

by Brandon White

Computer science major at Southern Methodist University

asha.org/public/speech/disorders/stuttering.htm
stutteringhelp.org
westutter.org



Developing Destinations for All

Increasing the Economy and Participation in Tourism

The tourism industry successfully reached one billion international travelers in 2012. While this represents strong growth, there are still great challenges for the approximately 15 percent of travelers who have a disability and need accessible transportation. Without this, they lack the ability to enjoy the full range of tourist destinations.

This lack of accommodation is one of the many reasons the Kéroul's organization was founded in 1979 in Quebec, Canada. André Leclerc, who's had cerebral palsy all his life and uses a wheelchair, became determined to help everyone arrive at their dream destination.

One of his major influences, Jacques Gilles Laberge, was general manager at the rehab centre where André stayed early on in life. Laberge firmly believed that traveling is educational for young people, and is one of the keys to furthering a person's inclusion in society.

A Destination for All is a town and tourist region where individuals with a disability and their families can be accommodated for days at a time, without the hassle of worrying about how they'll be able to get around and explore just like any other tourist. Beyond accessible hotels, restaurants and attractions, these destinations also have accessible businesses for everyday needs (grocery stores, malls, post offices, etc.), pedestrian routes and local transportation services.

The population of people with disabilities represents a growing market. Being accessible is a wise investment for businesses and destinations as a whole. Appealing to all travelers is a plus for the tourist industry, because it's a population that's motivated and eager to explore international destinations just as any other tourist would, which will, in turn, increase tourism.

Just imagine your 75 year old father or mother, who cannot move as fast as before, and can't climb stairs without being in danger of injuring themselves. Or think about the mother with a stroller who can't get into the bus or climb the stairs in the subway. All these people need a world where they can get around safely, and enjoy their stay at the destination of their choice. Accessibility is needed in every area of life for everybody to get a chance to discover the world.

Kéroul is continuing to move forward with the goal of "one world for everyone" by hosting a Destinations for All World Summit. The aim of the event is to exchange best practices for inclusive tourism; collectively develop international standards for accessible tourism; and establish a global partnership to create accessible destinations.

Leclerc has always known exactly where he wanted to take Kéroul, and never once did he question its importance.

"Believing is imperative," he says. It has been a lengthy battle, one he is still fighting, to turn Québec into the benchmark for accessible tourist destinations. And winning that fight may be easier said than done, since it requires convincing as many people as possible, including governments, public authorities, and the whole tourist and transportation industry.

Accessibility is the law; it's also good business. It's making a way for the future and a world we can all share. It's time to work together and realize that not only is adapting a world for all a moral right, but it's also beneficial to the collective economy. ■ ABILITY

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SHIJIE WEI

DREAMING BACK TO 221



> *"This time, it was an earth-shattering bang. The glass window behind me shattered to the ground. I felt the whole building shake and my body grew wobbly. I quickly rushed to the front door, pulled down the switch at the lab…"*
>
> -*Forbidden Youth* by Shijie Wei

The soul-stirring scenes depicted in *Forbidden Youth,* a memoir by nuclear weapons researcher Shijie Wei, replayed over and over in his mind for years. To many, his experience at the forefront of China's nuclear testing program remained unknown and deeply mysterious. As a scientist from 1964 to 1990, Shijie Wei first wrote about his 26-year career in a short story he published on China's Tianya website. In 2009, he serialized his account and rapidly gained a following of avid readers. So popular were his stories on Tianya's website that their hit rate soared into the millions. Eventually, they would be published as *Forbidden Youth*, which was adapted for television in 2012 in the hit series *Qinghai Flower* on China's CCTV8.

TOP-SECRET, HIGH-RISK WORK

In 1964, Shijie Wei graduated from the Physics Department of Theoretical Physics at Shandong University. Since he and only one other classmate passed the government background check, both were recommended for a "mysterious" job. But few details were disclosed to the young scientists, only that they needed to go faraway to Qinghai Province.

Xining City, located in Haiyan County within Qinghai Province, is the base for the 221 gold and silver nuclear research facilities, commonly known as the "Nine Courtyard." So secret is the location that it's impossible to find its coordinates. But, as far as the eye can see, the compound is surrounded by fortifications, power grids, sentry posts, and guards with guns and gleaming bayonets.

After the first three months of security training, Shijie Wei was assigned to work with the Socialist Education Production Team, a move he desribes as similar to going "down to the countryside." Here, he met his good friends Jiang and Lin. They were in the same group of colleagues who entered 221 with him. Lin and Shijie Wei began going on dates to Qinghai Lake, where they shared a few "bottles of water" as a keepsake of their love, which seemed fashionable at the time.

Wei and Lin talked about marriage: "At the time, I didn't have a house at the factory, so I lived in an old shed near the jobsite" said Shijie Wei. "We did some simple remodeling, installing a door and bed. There was nothing comfortable about it other than having a sufficient amount of electricity. We temporarily considered it our marital home. One day, Lin told me to look after our home, and then left on a business trip to Beijing. Who knew that this would be the last time I would see her."

In Beijing, Lin conducted neutron source experiments. Shijie Wei explains: "The experiment involved compressing as much nuclear material as possible and then injecting it into the nucleus. But neutron sources are highly unstable." Tragically, Lin had an accident during one of the experiments and was badly injured. The medical treatment she received failed and she died.

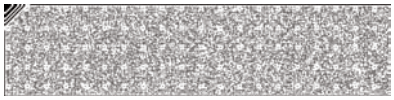
Back at the base, life went on for Shijie Wei. He became a basic grassroots technician and his work number was 218 Factory Second Branch. He was primarily in charge of researching explosive materials. "Nuclear weapons are divided into two parts: the middle contains the nuclear material, and the outside is comprised of explosive materials; it is your standard high energy explosive testing," he says. "I was the one who set the parameters for testing the thermophysical explosives: coefficient of expansion, thermal conductivity, specific heat, etc."

The benefits a nuclear researcher received were not bad. Shijie Wei earned a monthly salary of 120 yuan (nearly $20) for the county position he held at that time. But the risks were extremely high. One of Shijie Wei's co-workers, number 229, who worked very close to him, had an explosion. All the windows near the factory shattered and four workers were blown to pieces. The slightest mistake can cause a fatal accident at any given moment.

If the explosion is random, then it's inevitable that radiation exists. Nuclear radiation originates from uranium 235, which is the core element of all nuclear weapons. At the time, the station's response to an explosion was to send staff members a large number of photographic plates, plus sugar and tea. The photographic plates needed to be worn on the body every day and then taken off to be washed after work. If a photographic plate turned black, then that meant it had been exposed to radiation. It was a boorish idea, of course, to think that serving tea with sugar was any way to comfort people. "Even if the photographic plates turned black, they were still not a good solution," asserts Shijie Wei. "At the most, the health department would do a checkup, but the risky experiments continued."

Since Shijie Wei did research on explosive materials, he also had to bear the threat of exposure to harmful chemicals such as formaldehyde and acetone. "At that time, the only protective measure we had in place was to wear surgical masks. During the Cultural Revolution (1966-1976), it was wrong to overly emphasize personal protection, and we didn't feel any discomfort about it at that time." But, after a few years, the effects of repeated exposure to nuclear radiation began to show its harmful effects. Many of Shijie Wei's colleagues were suffering from liver cancer and crystallinity appeared on the retinas of their eyes.

After the Cultural Revolution began, the nuclear research factory's Deputy Ministers, Dongcheng Zhao and the Deputy Commander, Siling Fu, took control of







L to R: Rare family reunion daughter Haiyan, wife Chen, Shijie, son Gang. (photo Jiang Peng)

China's military. Angered by this decision, a large public riot ensued. According to Shijie Wei, "Out of more than 10,000 rioters, 50 committed suicide, 300 were wounded, and 3,000 were locked up." When the nuclear scientist tried to help one of the protestors, he was labeled a "killer." Of the eight people who volunteered to help during the riot, six could not withstand the torture and confessed to false charges. The remaining two were Shijie Wei and his friend Jiang. Shijie Wei was sentenced to one year and two months in prison.

26 YEARS COMPILED INTO ONE BOOK

In 1973, Shijie Wei married Weiying Chen in Mianyang, Sichuan, and had daughter, Haiyan Wei, and son, Gang Wei. During their time in Sichuan, Shijie Wei was assigned to the position of Project Group Leader for the Nine Courtyard Third Primary Institution and became a committee member for the Nine Homes Third Primary Academy.

On one occasion, Shijie Wei participated in a highly classified meeting of top-level scientists. The research content involved the future development of China's nuclear weapons program. Shijie Wei, representing the Third Primary Institution, wrote a report about the meeting. Participants included scientists Ganchang Wang, Jiaxian Wang, Nengkuan Chen and the founding fathers of "Two Bombs, and One Satellite," which marked the explosion of China's first atomic bomb.

This period of Shijie Wei's life he considers his happiest and most relaxing. The degree of secrecy at Nine Courtyard had loosened up a little, and the environment was less repressive. After work, he spent his evenings writing *Forbidden Youth* and completed many other popular science books.

In 1985, Nine Courtyard's name was changed to the Chinese Engineering Physics Research Institute. Due to their reputable publications, the institute's party secretary, Yingjie Li, transferred Shijie Wei to the propaganda department, serving as the editor in chief of the newspaper, *Twilight*. During this period Shijie Wei read a great quantity of documents and interviewed many relevant personnel.

It was the accumulation of his experiences during this period that influenced his decision to write *Forbidden Youth*. Some readers commented that, "Initially, it was the word 'nuclear' that attracted us, but the more we thought about it, the more we felt like what we were analyzing was not 'nuclear,' but the sentiment and history of the era." The book describes the complexity of Shijie Wei's encounters in love and life, as well as recounts in vivid, incisive detail his years of trials and tribulations.

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"The book is basically a true self-portrait with a little added artistic touch," he says, adding, "I actually did just three things with my life: nuclear research, write *Forbidden Youth,* and take care of my family.

Someone once asked Shijie Wei, "After writing *Forbidden Youth* and reflecting on the impact radiation had on your family's health, was it all worth it?" Shijie Wei laughed and said, "Actually, there is no question of it being worthwhile or not, but from the government's angle, I would say it was worth it. On a personal level, I would say there were no enemies to fight, but, still, I got injured."

AN OPTIMISTIC, DEVOTED FATHER

In China, Shijie Wei is highly respected and admired not only for his contributions to science, but also for his steadfast devotion to his family and his positive attitude. In 2013, on a popular microblog about a festival honoring Father's Day, a fan wrote:

"A 72 year old man, after 20 years of taking care of three sick family members and never once abandoning them, has published dozens of popular science books, given 300 plus lectures to audiences in the hundreds of thousands, and has constantly put out positive energy. When facing life's struggles, his laugh can light up the whole universe. Is he Iron Man? God? Regardless, he is a person who cannot be defeated or daunted. This festival belongs to him, our suffering, big spirited father!"

Now long past retirement age and more than 70 years old, Shijie Wei's challenges extend into his personal life. His son, Gang Wei, was diagnosed with a developmental disability in fourth or fifth grade. Today, at age 40, he has the intelligence of a six or seven year old.

Although Gang Wei lives in a house not far from his father, he is able to independently take care of his basic needs. "He visits everyday and asks for two yuan of pocket money to purchase *White Fur Girl* CDs. He likes to watch old films like *Tunnel Warfare*. Gang Wei also likes to listen to the radio and crank up the volume to a very high level. When the neighbors pull the plug, he cries out," says Shijie Wei, who often has to go to his son's dwelling place to handle disputes with the neighbors.

Shijie Wei's daughter, Haiyan Wei, attended college, which made Shijie Wei proud. But in 2000, his daughter began suffering from abnormal symptoms, including complications with eating and sleeping, as well as delusions about persecution. She was eventually diagnosed with schizophrenia and requires medication every day.

Shijie Wei cares for his daughter on a daily basis. If Haiyan Wei wanted to eat bananas, he would hurry out to buy them for her. The first thing he does when he wakes up every morning is put her medicine on the table, with the "morning, noon, and evening" labels written on top of each lid. To the side, there would be a small amount of sugar. Sometimes the retired scientist must face some pretty awkward moments: helping his daughter take a bath or purchasing sanitary pads for her. "If it was any other 70 year old man helping his daughter change sanitary pads, he might break down," said Shijie Wei's assistant, colleague and good friend Yueling Wang. "Old man Wei has had to endure bitterness all his life, but he has never said that he suffered."

In addition to his daughter, Shijie Wei's wife, Weiying Chen, was also diagnosed with schizophrenia. His wife would sometimes be stable, but other times her illness would take over. It recently became so severe that she won't even see Shijie Wei. "My wife is still at the hospital recuperating because she is afraid of someone harming her. When I go to see her, she won't even agree to talk to me one-on-one. She will pull me into the hall where there are people. She will give the doctors money and tell them to take her back."

His wife even attempted suicide. She once slit her wrist and nearly cut her arteries. Later, she developed diabetes. One time, while Shijie Wei was helping his wife comb her hair, with a clear mind, she said, "Husband, thank you for all your efforts all these years." After hearing these words, Shijie Wei shed uncontrollable tears, feeling both bittersweet and sad.

Once some old friends suggested he give up and look for a caretaker for his family and remarry. But Shijie Wei's response was adamant: "I have never thought of giving up, for fear that they would suffer abuse. As long as I am still alive no matter how much time I have left, I will take good care of them."

The retired scientist has already figured out how to take care of his children when he passes away: "Find a group of family and friends and organize a 'monitoring committee' as a go-to service. This would make me very satisfied."

But even in the face of personal hardship, Shijie Wei's days remain rich and meaningful. Aside from writing books, he volunteers to give science lectures to college students in his spare time. Sometimes he also participates in charity events. It is not unusual to see a bright smile on Shijie Wei's face. On the microblog, Weibo, he defines himself as a "Misfortunate Old Man," but this description, he insists, is merely banter. "I don't really feel misfortunate. I have had fortunate moments in my life, such as publishing several books, which I believe to be very good." ■ ABILITY

This story is part of a series of articles published as an exclusive editorial exchange between *China Press for People with Disabilities/Spring Breeze* and *ABILITY Magazine*

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TICKET TO *RIDE*

"I've got a prescription in my pocket I bet most people around here would kill for."

I was invited to the Americade Motorcycle Rally in Lake George, NY, to present a few seminars. Everybody thought my script was for medical marijuana! And they guessed wrong!

My presentation, MotoMedicine: Riding for Medicinal Purposes explores not only how riding a motorcycle on a regular basis is fun, healthy and a social good, but how riding every day might also be used for medicinal purposes, a treatment for all types of ailments. The golden ticket in my pocket was an official doctor's order to ride my motorcycle up to eight hours per day as needed to relieve my MS Symptoms!

For me, riding a motorcycle has become an intricate part of managing the progression, and treating the symptoms of my Multiple Sclerosis.

There are many known social benefits to riding motorcycles. They are more fuel efficient and less expensive than cars and trucks, easier to maneuver in traffic, take up less parking space, easier on the infrastructure, and motorcycles reduce traffic congestion tremendously.

Riding is also a physical, or moderately physical activity, a huge stress reducer, and loads of fun. You don't need to be a brain surgeon to understand riding on a regular basis is good for our planet, keeps the body in shape, mind focused, and refreshes the spirit. But what if—motorcycling could also be used to help treat diseases and illnesses?

I have been on my million mile quest for two years, have ridden over 70,000 miles, and have come to the conclusion that the more I ride, the better I feel, and the less my Multiple Sclerosis symptoms bother me. I am in better physical shape, and emotionally and mentally healthier as well. Since 2012, I have less fatigue, my memory has improved, and I am a hell of a lot happier.

I also notice on wintery snow days or anytime I had to ride in a car for a few days in a row, my physical and mental health deteriorate and my MS symptoms seem more pronounced! I told my wife the car was making me sick!

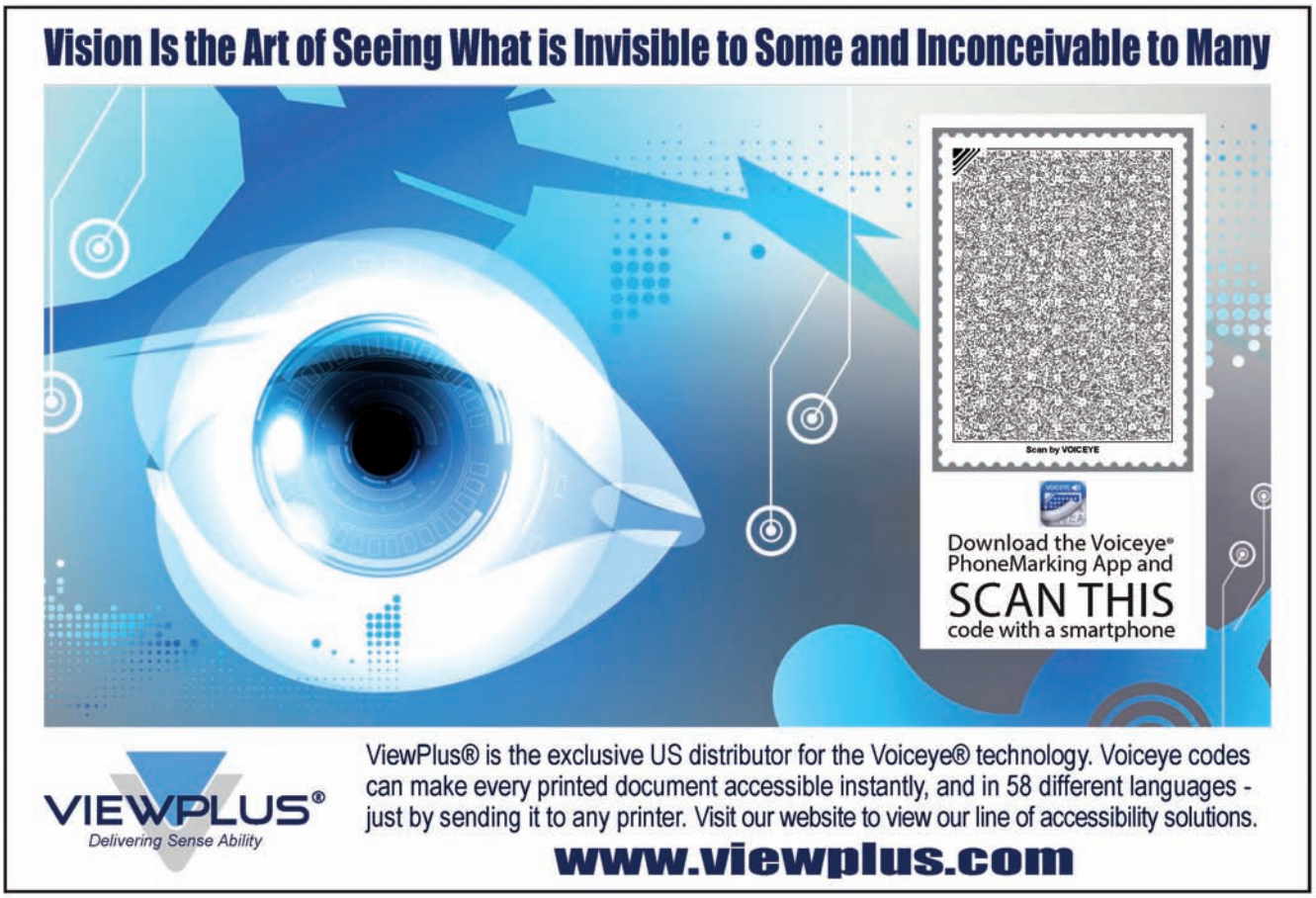
I realized, I needed to continue riding not just because I enjoyed it and because of my million mile pledge, but because riding was keeping me healthy and happy. Riding every day was keeping my disease from progressing and was actually alleviating my symptoms. It sounded crazy, but I wondered if riding a motorcycle could really be a serious part of treating an incurable, progressive and often disabling disease? Was I alone, or could riding a motorcycle every day also benefit other diseases and illnesses as well? I started to do some research, and found there were studies that showed I was not crazy! MotoMedicine is a term I created, and it means using motorcycles as a complimentary treatment and therapy to improve one's physical, emotional and mental health.

Riding a motorcycle is emotionally therapeutic. It is pleasurable, empowering, and inspires freedom.

Riding a motorcycle daily improves cognitive functions.

Two studies done by Prof. Ryuta Kawashima at the Department of Function of the Brain Imaging at Tohoku University in Japan found that the intense concentration necessary to successfully negotiate traffic and changing road conditions while balancing on two wheels has a stimulating effect on the brain, which is not stimulated by watching tv or driving in a car. Riding improves spacial reasoning as well as memory while reducing stress levels, and showed increased brain activity in the right hemisphere of the pre-frontal cortex. This is the area of our brains that handle memory, space recognition, information processing and concentration functions.

For me, improving cognitive function is huge because the parts of my brain that have been damaged from MS



the most are related to cognition, memory, multitasking and thought processes.

I didn't always have a name for it, but after returning home from a conference that cost me $1,200, my wife was explaining what mindfulness was when I suddenly interrupted her and said, "So...,What you're saying is... mindfulness is the same as riding a motorcycle?"

I had been practicing mindfulness while riding for years!

Mindfulness is a form of meditation, a state of active, open attention on the present. When you are mindful, you observe your thoughts and feelings from a distance, without judging them good or bad. Instead of letting your life pass you by, mindfulness means living in the moment and awakening to experience.

Studies have shown practicing mindfulness can bring a variety of physical, psychological and social benefits including increasing positive emotions and reducing stress. Mindfulness can also boost our immune systems, and may even be used as an antidepressant. Studies have found practicing mindfulness changes our brains by increasing grey matter which is linked to learning, memory, emotion regulation and empathy.

Motorcycling is an excellent way to practice mindfulness, riders are alone with their thoughts, focused, allowing the mind to be cleared of clutter; staying alert, being in the moment and experiencing the ride and the surroundings in real time.

When I ride long distances, my mind is often completely consumed with absolutely nothing at all. I am only in the present, in the ride, observing and reacting to sights, sounds and sensations, as they happen in real time.

I now know, this my friends is MotoMindfulness!

Realizing, and seeing actual studies to reinforce what I have felt for some time, I am now able to use riding to treat my disease. It took a little doctor shopping, but I am now under strict doctor's care and orders to ride my motorcycle every day possible for my health. It is a very tough pill to swallow, but yes, I have a prescription to follow my passion and to live out a dream. My medical team believes riding is indeed beneficial in treating my disease. Now, if I could just get my health insurance to pay for the treatment, it would be a perfect world!

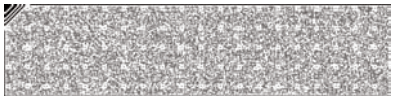
Check with your doctor to see if MotoMedicine might be right for what ails you.

WARNING: Medicinal use of motorcycles is addictive and riding daily may lead to serious side effects including an increase in overall better health, intelligence, peacefulness, self-worth, physical strength, lifespan; and for about half of us, riding a motorcycle daily may lead to an erection lasting more than four hours.

Off to take my meds. ■ ABILITY

Longhaulpaul

longhaulpaul.com





Lily's Big Picture

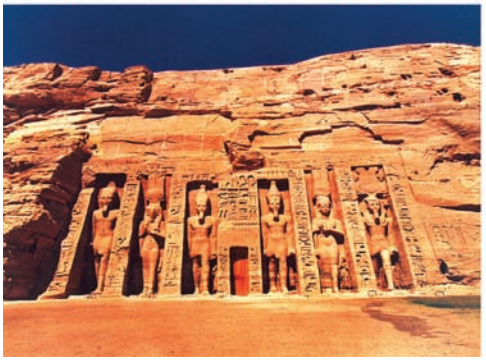
Photographer and advocate, Lily Bandak, and her colleague, San Diego State University professor and administrator Caren Sax, recently spoke with *ABILITY*'s Lia Martirosyan and Chet Cooper about bringing the link between travel, education, photography and disability into focus.

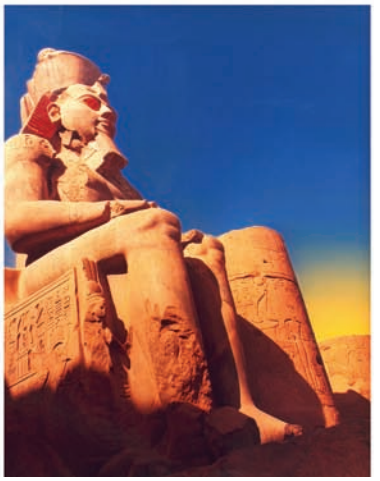
Chet Cooper: Tell us about your photography background.

Lily Bandak: My family is from Bethlehem in Palestine. We immigrated to this country in 1960, when I was in grade school; I went to high school and university here. From there, I went on to university in Paris and studied painting. When I came back here to the







University of Delaware, I decided to take a photography course, and loved it. Then I went to the Egyptian embassy to see if they would pay for me to take a trip to Egypt to photograph there.

Egypt has all this beautiful history; I wanted to capture it. When I came back in the mid-70's, Jimmy Carter was President, and I got an introduction to the White House photography department head. He liked my work, and wanted me to meet Mrs. Carter; she wanted to make my work part of the permanent White House collection. Everybody at the different embassies heard about that, and that's when I started doing work with all these countries.

Cooper: What was the state of your Multiple Sclerosis (MS) at that point?

Bandak: I was okay at that point. Then *Newsweek* heard about my work and approached me. They asked if I could cover the big civil war in Lebanon. The magazine had sent a lot of photographers to try to cover Yasser Arafat, and they had not been successful. Then they heard about me, and I could speak the language, and I am originally Palestinian. So they asked me to go to Lebanon to cover Yasser Arafat, so I did. I don't know if you heard about the massacre at Sabra and Shatila?

Cooper: No.

Bandak: In 1982, there was a big massacre in those areas, where they killed every man, woman, and child. And I covered it. That's when I got sick. That's when the MS started. My nerves just couldn't take it. I'm not that kind of photographer. I do art photography. In Washington, leading up to that experience, I met King Hussein at the White House. He gave me his card and said, "Why don't you come to Jordan? Here's my card. If you want to come, just call the palace."

(*laughter*)

Cooper: The words every photographer loves to hear…

Bandak: Yes. What inspired me to call was the fact that I was sitting in Arafat's office one day, and there was a bombing. This guy runs in with a hand, and says, "What should I do with this?" It was terrible. So I decided to call the palace, and they invited me to go there. When I arrived, I saw the Queen, whom I had met before. And she said she wanted me to teach photojournalism at a new university.

I started the first photojournalism department in the Arab world. But during the year I was in Jordan, apparently I had MS and didn't know it. I was able to walk, but I started to have problems. I had to use a cane, and my leg would be hard to lift. So King Hussein sent me to London to see a neurologist, who diagnosed me. I

didn't believe him. So I came back to the US, and went to Johns Hopkins and the University of Pennsylvania for a second opinion.

Cooper: When were you diagnosed, and how did that affect you?

Bandak: I was diagnosed in 1984 and decided to quit teaching. I came back to the US and sat around for two or three years; I didn't want to see or talk to anybody. By then I was in a wheelchair and thinking, "How can I do my photography in a wheelchair?" But then I began to get physical therapy, and my therapist told me about an assistive technology center. "Why don't you go and see if they can help you?" she said. So I did.

They told me, "There are wheelchairs that elevate. You can photograph high places." I didn't think I could do that in a wheelchair. They said that my wheelchair could also decline, and that it could do a lot of things. And they built a camera mount for me on the wheelchair. That's when I started to go to the Middle East. At the time I was still able to use my hands. And since I was a journalist, I knew a lot of other journalists. In Washington, a friend of mine named Maureen Bunyan, who was well known for her TV show, got in touch with me. I told her. "It's been a few years since I've worked, and I need somebody to sponsor my trip."

Lia Martirosyan: You were a great networker.

Bandak: I always had help. I don't know how she did it, but Maureen got in touch with the wife of the ambassador of Saudi Arabia, who also happened to be the daughter of King Faisal, and was living in Virginia. They have a big mansion there. Maureen called her and was told: "You can bring your friend, and the Princess will meet her." After I met with the Princess, she sponsored my trip to the Middle East. I traveled in my wheelchair, and took a nurse with me. In Jordan, I got in touch with the Lebanese embassy, which arranged for me to go to Lebanon and try to do photography there in my wheelchair.

They also arranged for me to go—have you heard of Hariri in Lebanon? He was the Prime Minister back then. His people arranged for me to go and meet with his sister—who was a member of the parliament—as well as his wife. I asked if I could take photographs. They looked down at me, because I'm in a wheelchair and didn't think I could do it. So they said, "Okay" just to humor me. And I took pictures of her and her whole family. And when I came back to the US, I developed them and sent them to her.

Martirosyan: Did anything come of it?

Bandak: Later. One morning, at 7 o'clock when I was sleeping, I got a phone call. The Prime Minister's sister said she couldn't believe a person in a wheelchair could do such a nice job, and she would like to invite me back to Lebanon to do a show. And the First Lady of Lebanon, she came and hosted the opening. It was a big story, and all the newspapers and TV stations covered it. The TV station, which is owned by the royal family, did an interview with me.

So as I became popular in the Arab world, I asked them: "Why don't I do something here to get people with or without disabilities to study assistive technology?" Because I was doing all my photography through assistive technology. I saw the need, and have been trying to get more people into it ever since.

Cooper: I wanted to interject one small thing. Those three years that you said you hid away after you were diagnosed; you weren't alone in the sense that over 50 percent of people with MS have clinical depression as a symptom.

Bandak: Yes. Fortunately it doesn't affect me as much now. And back then there was so much that I had to give up when I came here. For instance, around that time my house caught on fire.

Cooper: We heard about that.

Bandak: All the negatives, all the pictures were destroyed. The only reason I moved here was because my mother has Alzheimer's. She can't even recognize her kids sometimes. It gets me very depressed. I'm trying so hard to do my work, and I really need help to get this project going. I've been trying for the last 20 years to get these kinds of studies going.

Cooper: I remember during our joint expo at CSUN, ABILITY *showed some Chinese art, and you showed your work- you still have a lot of beautiful pieces. Do you have any of those in digital files?*

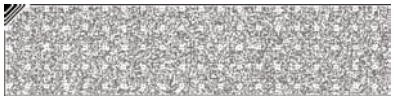
Bandak: I have some, yes.

Cooper: That's good. Please tell us more about your assistive technology project?

Bandak: When I lived in Washington. I met with a Prince of Saudi Arabia at a conference. I told him about this program, disabilities, and my idea that they might send some students to study assistive technology. Then he went to Saudi Arabia and talked to some people at a Center for Disabilities. And they sent somebody to San Diego, because I had moved here. They talked to me and Caren, became convinced that this assistive technology program could work, and sent a student with a disability, who is now a second-year student with Caren.

Cooper: So that paid off.

Bandak: Yes, it has. Now I'd like to continue this pro-





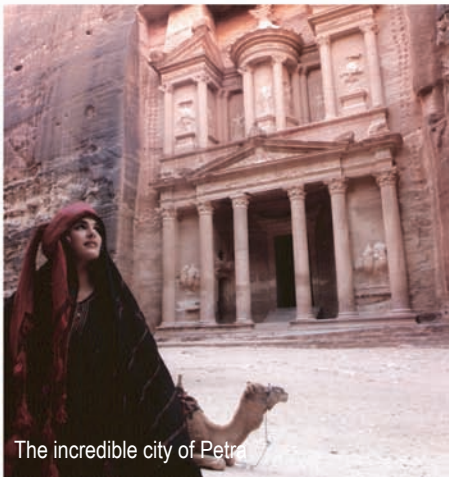






Lily capturing King Hussein & Queen Noor frame by frame





The incredible city of Petra

gram with other countries in the Arab world. And I was thinking, since all these companies are there, maybe they could help with sponsorships. What I would love to do is get a building to house the program. The problem was, the girl who came here to study the program, she's had challenges. First of all, she has a disability, so she brought a caregiver with her, and the caregiver didn't have a visa, and they had to send her back. So I thought it would be great if we could have a home for students who are disabled, because they're going to have a hard time. This is a different country. They don't know how to get back and forth to their classes. They don't have anybody to help them.

So if we had housing and other facilities for them, we could support these students when they come to study in the program.

Cooper: So part of your concept is to provide housing and support, as in assistive housing?

Bandak: Yes, that's what I would like to do. And get a van to take them to school. I would like to start something like that.

Cooper: What about the curriculum itself? Has that all been established?

Bandak: Yes, I got the curricula from Caren. There are a variety of 16-week courses that they can take, and there is also a path that can lead to a degree, if they want one. That will take a few years.

Have you heard of ADC? It's the biggest Arab-American organization. It's headquartered in Washington. American Arab Anti-Discrimination Committee. Dr. Clovis Maksoud, you met him. His wife was the president. Clovis used to teach at American University; he had his own department. Do you know anything much about him?

Cooper: I know that he has a book of his memoirs, and I was thinking about looking at it, because he gave a brief background which was pretty impressive.

Bandak: Clovis was the Arab League ambassador for 15 years. He's now a UN advisor. His wife was the president of the ADC. Clovis was also the editor of the biggest newspaper in the Arab world. I've known him for 30-some years. He is on the board of my non-profit. At his age, he does so much. I wish I were in Washington. I could get things done a lot faster there.

Martirosyan: What would you like to get done faster?

Bandak: There isn't one assistive technology center in the whole Arab world except in Qatar, and the one there is run by someone from England. They always

have to bring somebody from Europe or the US. I would like to bring people to learn about assistive technology so they could go back to their countries and help people with disabilities.

I get emails from Lebanon, which has a high percentage of people with disabilities. They really could use that. I've been in touch with the American University in Beirut. It's a great school, one of the best in the world. And I got in touch with the dean about starting a department, they could just add an assistive technology component to the computer department they already have. The University of Delaware's computer department has an assistive technology component that addresses disability. The University of Delaware is working on robotics. I don't expect that in the Arab world, but anything simple to help them would be an improvement. But the AUB wasn't interested. There are a lot of people with disabilities who could benefit from these technologies that I use.

Cooper: By assistive technology, you mean the full scope of technology, not just computer access?

Bandak: Yeah, it's not just computer access; it's environmental controls. It's a lot of things. In the Arab world, people who are disabled would like to be able to control their TV. It'd be great if you can't use your hands to have controls like I do, and to be able to turn the lights on and off.

Cooper: Do you do a lot of Skyping?

Bandak: Yes, I Skype. I'm so far away from everything. When I was living in Delaware, if I wanted to get things done, I would go to a politician. Here, if you want anything done, you have to go to Sacramento. That's pretty far for me to go. Like, my senator in Delaware was Joe Biden. He did so much for me. I'm hoping that Clovis and the Ambassador will come as they said they would.

Cooper: Yes, in September.

Bandak: I hope we can get things going.

Cooper: You mentioned that you've already had a student out here.

Bandak: We've had more than one student from the Middle East. We had that one girl who came from Saudi Arabia sponsored by the prince, and there's another girl from Iraq. She's studying to get her master's. She comes here a lot, and said she would love to meet with the Ambassador and talk to him about the program.

Cooper: You mean she comes to your house?

Bandak: Yes.

Cooper: And she's also in the assistive technology program?

Bandak: She's with the rehabilitation department at the university, and they have classes in assistive technology.

Cooper: Are they typically students with disabilities, or without?

Bandak: With and without. Some people with disabilities can learn to help themselves, and they also want to learn so that they can help other people with disabilities, such as in nursing.

In assistive technology, they can get a master's.

Cooper: Your concept includes housing the students, are you looking at getting an apartment building?

Bandak: It doesn't have to be an apartment building. It could be a really big house, like I did this one. This used to be about four rooms. I opened it all up so I can get around in a wheelchair. Everything is accessible, the bathrooms and everything. There are a lot of people here from Iraq, by the way. They need jobs. We could get them to drive those students to and from school. And they speak their language, so that would be helpful. I can get people like the girl who just left. She's from Iraq and works for me. You've been to Jordan? To Petra?

Cooper: Yes.

Bandak: Twenty years ago, I wanted to photograph Petra so badly. And Queen Noor helped me so much; she got me a truck from the army, and they put in a ramp so I could roll up onto the truck. They took all the seats out, and I went down there and photographed Petra. Everybody would see me in the street and they would stop. They couldn't believe it; it was the first time they saw somebody in the street with a wheelchair.

Cooper: When you say that, do you mean a large power chair?

Bandak: Yes, a power chair. You didn't see many people in wheelchairs in the streets 20 years ago. Maybe now, I don't know. About six or seven years ago, I got an email from the State Department. A friend of mine said, "Read this article." It was about an organization for kids with disabilities that was trying to raise money. They were selling the paintings their kids did. But at the event, only the parents showed up. They didn't bring the kids because they were too ashamed to show them. You know?

But through assistive technology, the kids are able to do things. They're able to go to school and learn, to be regular people in society. The reason their parents were ashamed of them was because they couldn't do anything. But I think assistive technology can help them do a lot.

Cooper: We met the person from Al Jazeera's Washington office. Tell us the story about him.









Cooper, Martirosyan, Ambassador Al Kuwari and Dr. Clovis meeting in DC

Bandak: In 2008, he interviewed me for Al Jazeera. He even sent people to Delaware to come and photograph my house, and the apartment controls. He was great. I asked him at that time if he would be a member of my non-profit and he said yes, he would. He and Clovis have been behind me.

Cooper: How did you meet Dr. Clovis?

Bandak: I met him in the late 70's.

Cooper: At a Disco?

Bandak: (*laughs*) No, he was the ambassador of the Arab League. At that time I was a student. It was around 1978. That's when I told you I was looking to get somebody to sponsor me to take a trip to the Middle East so I could go and make photographs. So I went to him.

Cooper: You've stayed connected all these years?

Bandak: Yes. His wife would come to my exhibits, and she bought some of my work. I used to call her every night before she died. We became pretty close. I would tell her, "Don't give up hope."

Cooper: Clovis seems like a really sincere person. When we met him, he said, "I just told Lily how illiterate I am on the subject [disability], to expect the worst. It might not be the worst, but one grade above worst," and we laughed, and he went on: "We think that by helping communicate our deficits in knowledge and commitment, we might be able to have others emulate that, and become interested in support and empowerment for the people who are in this category."

Caren Sax: You met Dr. Clovis?

Cooper: We met him and Ambassador Al Kuwari. They're looking forward to coming out.

Sax: I met with them when I was in Washington, DC in April. That's what they talked about.

Cooper: Do you have a lab set up?

Sax: No, there's no lab. Our students learn and do the work in the community where there are other centers. We could go to the high-tech center at San Diego State; there are high-tech centers at every community college in the area. Most of them have our graduates who work there. The independent living center has AT services, the center for the blind. There are a number of places that we access for student training.

Cooper: If I understand you correctly, there are only a couple of students who've come from the Middle East thus far.

Sax: We have a new one coming this fall. We've talked a lot about raising awareness in the Middle East around disability and using assistive technology as a vehicle to do that. But at this point, a lot of the work that we do in my institute is more capacity building than "we'll come in and do this for you." That's more the approach, and they were obviously very interested in that. The student we have in the program now, and the one who is coming, are both very interested. One, from Kurdistan, will be graduating this year. She would like to see things change. She's in my assistive technology specialization, and is interested in helping.

But bringing one student over at a time will limit the impact, so the idea that Lily and I talk about is having one country or a group of them support smaller groups of students with scholarships. It's much easier to effect change if you've got a group of people who have common knowledge and complementary skills, than one student going back and saying, "Okay, I want to change the

world!" And we know that. We've all been involved in change efforts, and change comes slowly. In the Middle East, they've got a whole lot of other things on their mind rather than doing this work.

Bandak: Look what is happening with all these conflicts. It creates more people with disabilities.

Sax: That's right, more and more people. So the idea is to bring in a cohort of students, whether from one country or small cohorts supported by several countries, who would come here to study together. We would work with our language institute if there are language issues. I know Nora, who has been with us a year, and her English is very good, but she felt like she wanted to take some classes through the language institute more for writing, so she took some classes. We had her take one of the rehab classes just to get started while she was finishing up her English classes, and she's doing great. She's got a disability herself, so she knows. She's had treatment, knows how people get treated and is very interested.

The student coming in this fall started at another university. It's very difficult for her. She was in a place where there were no other people there from the Middle East. When she first got there, some of her family members came and it was fine. When they left, she just couldn't cope.

Cooper: What country?

Sax: She's from Saudi. She went to school in Arkansas. You can't imagine. It was so isolating. She heard about our program and wanted to come here. She's already gotten connected with the Saudi community here. I got her connected with Nora. She already feels like she's coming to a place where people will support her. That's really huge when you're leaving your family so far away. So the idea of bringing a cohort would make a big difference.

We also went to the international education conference here in San Diego, and met some folks who are the middlemen and bring a lot of students over. We made a good connection with them, and they're very interested in the program. The guy who runs that has a son with a disability. Actually, both the people we met from the organization have kids with disabilities.

In fact, within a few days they called me and told me of a student who might be interested and I said, "Have the student call me."

Martirosyan: What about the difficulty level of being accepted into San Diego—

Sax: If you're international, if you're out-of-state, it's much easier to get in. And they will work with me on that. That's no problem. As an undergrad, they're getting 50,000 to 60,000 applications for around 9,000 slots. But if the student is international, especially at the graduate level, we have a little more control.

Bandak: Do you know if they offer scholarships for students to come?

Sax: They're paying for students to come to our program. We've had other students from the Middle East, and they all got funded by their governments.

Bandak: Like Nora, the Ministry of Education is paying for her to study here.

Sax: And the new student who's transferring from Arkansas, they're paying for her, too. But the one who graduated a few years ago—they wouldn't even let her stay to do the program. Our 60-unit program usually takes two-and-a-half or three years, but she was required to do it in two years, because they only wanted to give her funding for two years, and it's difficult to do this program in that short a time. Nora isn't being required to do that, so I don't know if that changed. We write a lot of letters to do all this stuff to support the students.

Bandak: In the Arab world, the Qatar Foundation is all about education, and Caren's program is educating people about assistive technology. They should include this in their education, because they're trying to address people with disabilities. If you look at the Qatar Foundation, you'll see. They could include assistive technology education.

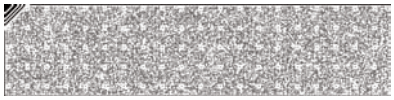
I want to facilitate their stay here. When I went two years ago to Abu Dhabi to speak at the university, I met with a lot of girls who are interested in my program. The thing is that their families wouldn't send them here, because they're all covered, and they're very strict. But if we had housing for them—

Cooper: —their parents might feel more at ease.

Bandak: Yes. They could feel easier about sending their girls. When we went to the presentation by the Gulf countries at this international education conference, and they were reporting on some surveys that they had done with students and what areas they did well in, where they were struggling, not academically but socially, what kind of support they got, what kind of supports they sought out, it was very interesting.

There was a lot of information that ultimately wasn't terribly different from what we see for all students going away to college for the first time, when they're not home with Mom doing everything. And that's not so very different from a lot of freshman. You know how—when they send foreign students here—there are families who host them? Arab families will host. That can be arranged. That would make everybody feel so much better. ■ ABILITY

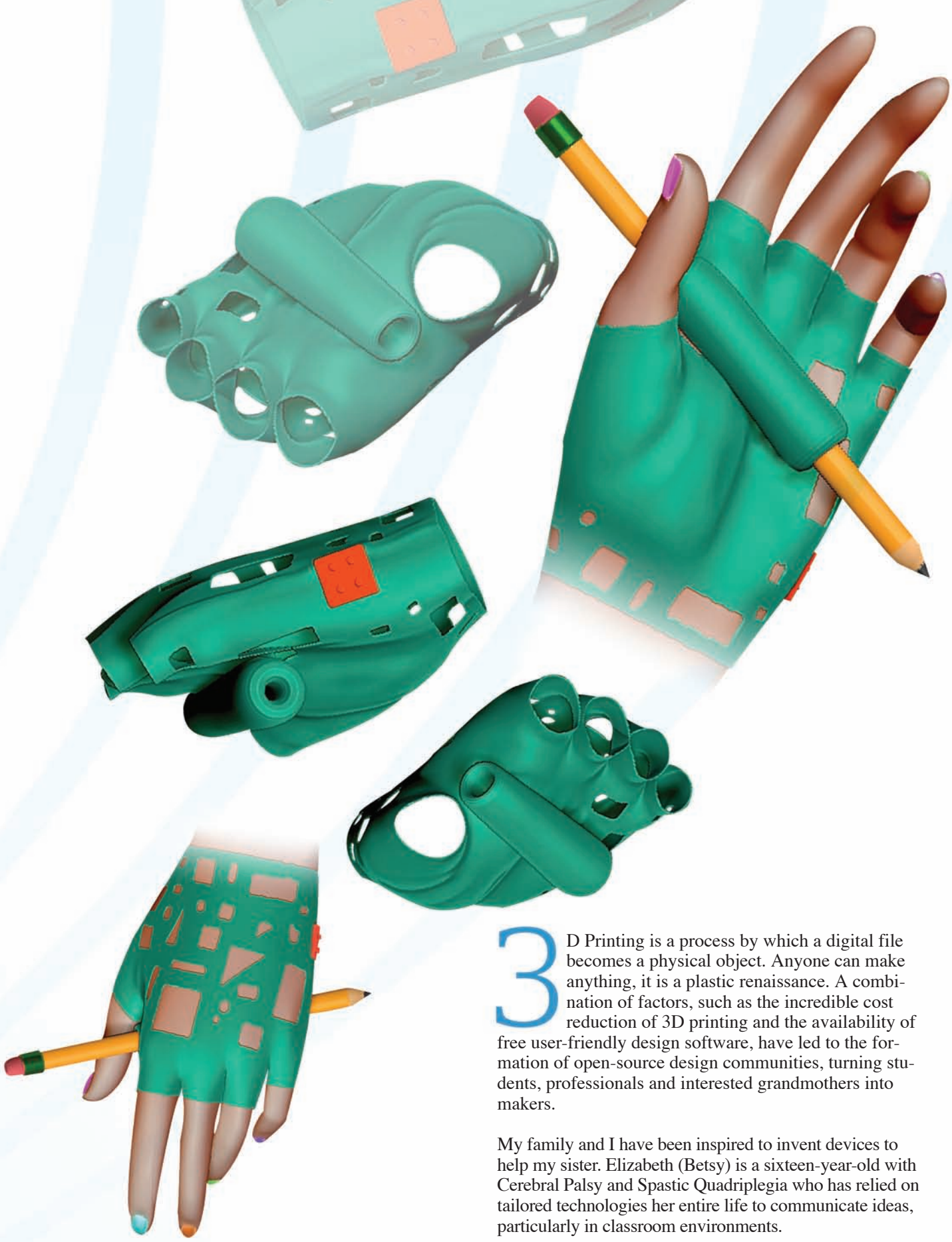
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3D AND ME

How can 3D printing promote inclusivity and agency?



3D Printing is a process by which a digital file becomes a physical object. Anyone can make anything, it is a plastic renaissance. A combination of factors, such as the incredible cost reduction of 3D printing and the availability of free user-friendly design software, have led to the formation of open-source design communities, turning students, professionals and interested grandmothers into makers.

My family and I have been inspired to invent devices to help my sister. Elizabeth (Betsy) is a sixteen-year-old with Cerebral Palsy and Spastic Quadriplegia who has relied on tailored technologies her entire life to communicate ideas, particularly in classroom environments.

My father Sergio Fernández, has a background in computer engineering, and in the past few years has created








multi-platform apps, including various educational apps, among them Memory4You, a successful vocabulary and memorization game that topped educational iTunes charts upon its original release.

One of the most exciting recent projects is a system that allows Betsy to command various aspects of her environment through movement and voice commands. The system is a modified XMBC (an open-source media player), and relies on visual feed from an Intel Perceptual Camera, capable of 3D rendering and infrared. The system is able to detect and distinguish Betsy's subtle and rather inconsistent motion signals to produce simple commands, such as skipping an episode on Netflix. Betsy is very opinionated about television and takes great pleasure in skipping ahead to her favorite episodes of The Fresh Beat Band.

As her oldest sister and a teacher of students with varying learning styles, I am familiar with Betsy's delights and frustrations. Promoting her agency is of utmost importance to me. Her particular challenges were the first to inspire my design and fabrication projects in this area:

One of my sister's challenges is difficulty maintaining a consistent grip of writing utensils. She either focuses on holding it really tightly and can't move her arm in the desired direction, or tries to follow through with the movement, loosens her grip, and drops the pencil.

Other children with CP face similar coordination difficulties.

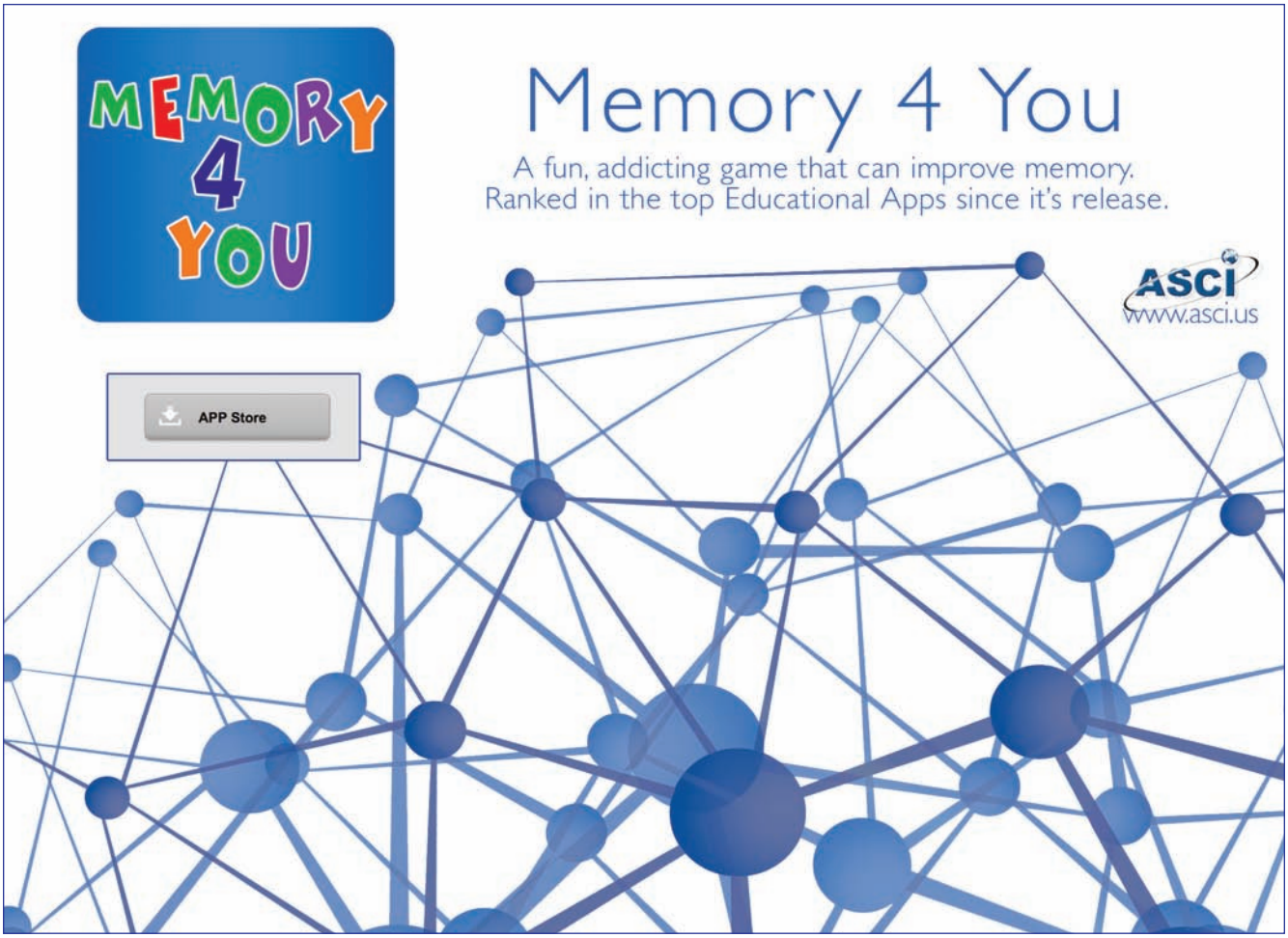
I designed a light, flexible glove with a built-in pencil grip, allowing my sister to shift attention from keeping her hand tight, and focus on directing utensil placement on the page, without sacrificing dropping the pencil or marker.

Another example of an assistive prototype I have designed for Betsy is a swimsuit with a built-in flotational headrest, helping her keep her head out of the water while she is in the swimming pool - her favorite activity. I have not tested this design yet, but a prototype will come soon!

Personally, I am interested in digital fabrication as a way of promoting inclusivity in education. As a teacher, I have seen digital media processes enhance learning and creativity. I first became interested in fabrication as an undergraduate art student. Having explored the capabilities of parametric design programs through my art practice, I felt comfortable approaching projects in assistive technology that require technical precision.

With this type of design thinking occupying most of my free time, I fell into conversation about assistive technology with a occupational therapist, Debra Fisher, who teaches young children of differing abilities through weekend programming at one of the museums where I work.

She mentioned a few students of hers wanted to participate in sidewalk chalk drawing activities, but had difficulty holding a stick with chalk attached to the end whilst driving the power chair at the same time.



She envisioned a device that could attach directly to the chair, so kids could draw, and practice shaping letters with their entire bodies. I was excited to try and design such a contraption and have since generated a few prototypes.

It has been so much fun to approach each consideration with a new and improved draft. The device has to attach to wheelchairs at varying distances, have a good grip on the chalk, keep the chalk grounded, move up and down with the pavement, withstand curves, etc.

My design work aside, the total material cost of generating three plastic prototypes towards the realization of this project has fallen well under ten dollars.

Design communities across the web have begun producing cost-effective plastic creations that can change lives. Files are free to download and modify, so designs become cleverer with every new iteration. I am a recent member of e-NABLE, a growing volunteer initiative dedicated to creating prosthetic hands. Even the most rudimentary prosthetics traditionally cost thousands if not tens of thousands of dollars. 3D printers are commercially available for under two thousand dollars, and can print you a hand for tens (or even ones) of dollars.

The cost-reduction in prosthetics has already made an impact around the world. For instance, a hospital in Uganda uses their 3D printer to generate prosthetic limbs for children in under 24 hours. Easily modifiable 3D files make it easy to customize an invention that can make a tremendous difference in a persons life. Design in this area is still imperfect in many cases, but the low cost of printing and open-source file sharing mean it can only improve with every draft.

On Thingiverse, the largest open-source 3D file host site, community members have invented and shared creations such as portable ramps, braille files, and adapters that connect to common hardware. Anyone with access to a 3D printer can download and print out these inventions. Designers can modify and repost a new version. It is easy to give credit to the original design and customize a new version that meets individual needs.

3D printing has begun to show its potential as a process that can promote agency and ability. I am excited to continue with this type of design practice, and have started a site dedicated to making inventions for the special needs community come true. Anyone can share proposals for creations that we can plan, design and actualize as a team. I am confident that 3D printing will continue to make a positive impact, and I can't wait to see what comes next. ■ ABILITY

by Ana Fernandez

customplastic.wordpress.com

SPECIAL OLYMPICS 2014



Steve Pelletier from Prudential at the SO Healthy Athletes ribbon cutting ceremony

The 2014 Special Olympics USA Games recently attracted 3,500 athletes from throughout the country to a weeklong celebration of the human spirit in locations throughout New Jersey. The events' participants helped shatter perceptions about what people with intellectual disabilities can do.

After four years of training, planning and preparing, the athletes competed to win gold, silver, and bronze medals in 16 different sports competitions: aquatics, athletics, basketball, bocce, bowling, cycling, flag football, golf, gymnastics, powerlifting, softball, soccer, tennis, volleyball, along with the two new demonstration sports, baseball and a triathlon.

The athletes couldn't have performed at such a high level, if they hadn't had the support of 1,000 coaches, 10,000 volunteers, and an estimated 70,000 spectators. This was also the most inclusive Special Olympics to date because the competition included individuals with intellectual disabilities and those without who played on the same team together in 10 of the sports. Those events were basketball, bocce, bowling, flag football, golf, soccer, softball, tennis, triathlon and volleyball.

SO Games founding partner 21st Century FOX provided on-air and online media exposure across its cable and broadcast networks, as well as on its local stations. FOX, for the first time ever in games' history, also aired a one-hour recap chronicling the weeklong celebration on its Sports 1 station. The show, *Celebrating Champions: 2014 Special Olympics USA Games*, captured the passion, dedication and determination of America's most inspiring athletes.

In addition to training, competition, education, and community building, 2014 athletes also had access to Special Olympics' Healthy Athletes program. It provided free health examinations and additional access to health care. People with intellectual disabilities are one of the most medically underserved populations in the United States, and even those who may have access to healthcare may not have seen doctors trained to suit their needs. Through Healthy Athletes, doctors, dentists, and other health professionals also get additional education and training needed to care for the ID population.



Actor John C. McGinley & ahlete Marissa Faralli taking turns at the podium



SO USA Games Youth Summit - teamwork session



Tim Fraizer & Kate Goorland writing a song reflecting their experiences

During games week, more than 100 high school students with and without intellectual disabilities met at the 2014 Special Olympics USA Games Youth Summit. There were leaders from within both Project UNIFY and Special Olympics' education and sports-based programs, which are powered by an engaged youth community. This alliance increases athletic and leadership opportunities for students with and without intellectual disabilities, and also creates communities of acceptance for all.

Project UNIFY is a youth-led movement, meaning that high school and university-aged students have the unique power to positively impact their school communities by promoting social inclusion. Those who head up the project are called Inclusive Youth Leaders: "inclusive" because a leader can be anyone of any ability level; "youth" because they have the passion and enthusiasm typically associated with young people; and "leaders" because they are the primary agents for positive social change within their communities.

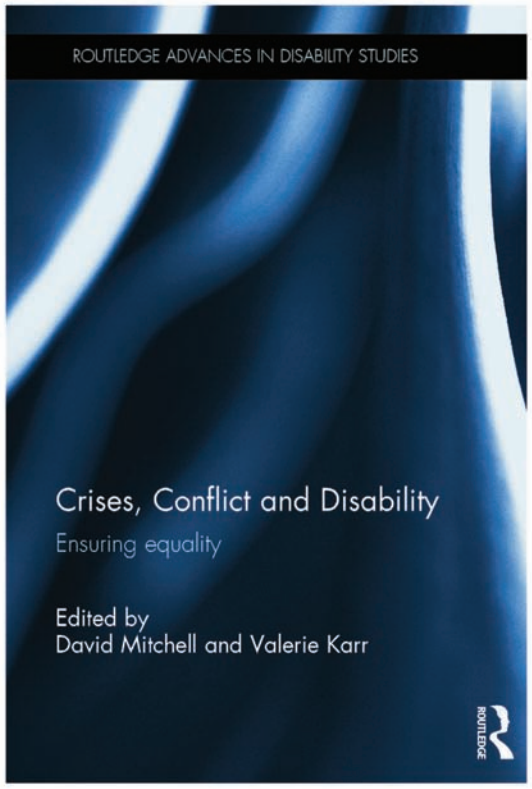
The message of the Youth Summit was simple: Play Unified. Live Unified. Unified remains a revolutionary concept—just as revolutionary as SO founder Eunice Kennedy Shriver's pioneering work for social justice. She believed that young people, with and without intellectual disabilities, could work together towards a greater victory than either could achieve on their own.

Students participated in summit leadership sessions that strengthened their abilities in communication, teamwork, co-leadership (pairing of one person with an intellectual disability and one without) and environment. Additionally, youth leaders conducted three school assemblies on Special Olympics and Project UNIFY, focusing on the outcome of friendship to select middle schools in the New Jersey area. Lastly, all youth summit participants organized and staffed a Unified Sports Festival to bring together people of all ages and ability levels to participate in Unified Sports. The festival featured soccer, bocce, football, kickball, Zumba and Wiffle ball.

All who attended the 2014 games were agents of change for inclusion. Stay tuned for the launch of our new youth activation campaign coming soon to a level playing field near you! ■ ABILITY

specialolympics.org

AN EXCERPT FROM



People with disabilities are among the most adversely affected during conflict situations or when natural disasters strike. They experience higher mortality rates, have fewer available resources and less access to help, especially in refugee camps, as well as in post-disaster environments. Already subject to severe discrimination in many societies, people with disabilities are often overlooked during emergency evacuation, relief, recovery and rebuilding efforts.

Countries party to the UN *Convention on the Rights of Persons with Disabilities* must take all necessary measures to ensure the protection and safety of people with disabilities during situations of armed conflict, humanitarian emergencies, and natural disasters. Such aid should be designed to support preparedness, response, recovery and rebuilding. This book includes perspectives from around the globe and explores the implications at the policy, programme and personal level.

Spotlighting a pressing issue that has long been neglected in emergency planning fields, this book discusses how to meet the needs of people with disabilities in crises and conflict situations. It is an important reference for those working in or researching disability and inclusion, and emergency and disaster management.

CHAPTER 28

DISABILITY IN BANGLADESH: THE EVOLUTION OF PROGRAMMES AND SERVICES – *SAIMA HOSSAIN*

Bangladesh, a country no larger than the State of Wisconsin, has a population of over 160 million people. It is currently one of the top three most densely populated countries in the world. In centuries past, Bengal, as it was known, was the centre of culture, learning, and trade, yet today it is struggling to earn the right to be called a middle-income country. Though rich in natural and human resources, persons with disabilities, particularly those living below the poverty line, remain the most vulnerable members of society in conditions of war, political strife, exploitation and a lack of planned development of infrastructure and social safety net programmes.

Adding to the many challenges facing the country, Bangladesh is a delta region that experiences floods, minor earthquakes, droughts, tsunamis, cyclones and soil erosion. Environmental changes brought about by global warming have resulted in an increase in the frequency and intensity of many of these natural disasters, thereby increasing the number of people who are displaced, impoverished and also disabled every year. Compounding the environmental challenges, the people of Bangladesh are also frequently victimized by recurring political conflict and acts of terrorism. This chapter will briefly summarize how service provisions for people with disabilities have evolved in the country despite limited resources and competing needs.

BACKGROUND

Bangladesh was declared an independent state from West Pakistan in 1971 after an intense nine month long civil war. However, the history of persecution of the Bengalis does not begin and end there. The political, economic, and social persecution began soon after the creation of East Pakistan in 1947. From 1947 to 1971 all economic and social development programmes remained where the government was seated in West Pakistan despite the fact that the industries, farmlands, and majority of the population of both Pakistans were in the eastern province. During the civil war, nearly three million people were murdered and thousands of women and girls were raped during the genocide. In addition, roads, bridges, and factories were destroyed, and many of the educated elite were assassinated by the military. Only three short years after its birth, the country was again thrown into turmoil with the assassination of its founder and first president Bangabandhu Sheikh Mujibur Rahman (along with 18 members of his family) as a result of a coup d état. The return of military dictatorship meant that government policies for the next two decades paid little attention to the needs of those with disabilities, despite a constitutional mandate for equality and nondiscrimination.

In 1991 the parliamentarian system was once again restored and the Bangladesh government was mandated by the people to follow the spirit of the Constitution.

Article 28 of the Constitution states:
The state shall not discriminate against any citizen on the grounds of religion, race, caste, sex or place of birth and that no person shall be subjected to any disability, liability, restriction or conditions with regard to access to any place of public entertainment or resort or admission to any educational institution.

This Article has formed the basis for all human rights mechanisms in the country, including its laws and policies, and has also allowed the state to accede to all such international human rights instruments.

The Ministry of Social Welfare was created in 1971 with the express purpose of addressing the needs of disabled war veterans, abandoned women, orphans and other minority groups. It is responsible for implementing programmes that provide allowances, aids and grants for the elderly, persons with disabilities and acid burn victims. It runs programmes that are multidimensional and their primary purpose is to see to the welfare of those who are 'bypassed, disadvantaged segment, unemployed, landless, orphans, distressed, vagrants, socially, mentally and physically handicapped, poor, helpless patients, juvenile delinquents'. However, no comprehensive policies and programmes were undertaken until 1995 when a national policy on disability was adopted. This formed the basis for new policies and programmes by the Ministry and also resulted in the formation of several NGOs focused on conducting research as well as implementing programmes and services developed specifically for the needs of those living below the poverty line. In 2001, Bangladesh passed the Disability Welfare Act and set up an inter-ministerial task force on disability and has made significant strides towards meeting the goals of the UN Convention on the Rights of Persons with Disabilities (CRPD).

CRISIS, CONFLICT AND OTHER CHALLENGES

The geographical location of Bangladesh is such that it is prone to cyclones/tornadoes, earthquakes, floods during the monsoon season, and droughts. As these natural phenomena have become somewhat more severe in nature, their impact on the population has also increased due to greater deforestation, urbanization, and pollution, etc... According to the Disability Rights Watch Group, the last 35 years has witnessed 38 severe cyclones, two of which resulted in extreme loss of life and property: Cyclones Sidr in 2007 and Aila in 2009, to which can be added Mahasen in 2012. These events have affected the livelihood opportunities of everyone living in the affected areas, in particular the most vulnerable of the population: those with disabilities who are living in poverty. In addition, the lack of proper urban planning and poor housing structures result in physiological injuries, and therefore an increase in the number of persons with disabilities. Flying sheets of corrugated metal are one of the causes that have been recorded as a reason for loss of limb and life as reported by the Centre for Services and Information on Disability (CSID) in 2002. It stated that the increased use of tin roofs in rural homes (from the traditional thatch) can actually become a safety hazard during thunderstorms and tornadoes. In crowded urban areas, structures are being built without adequate planning and regulation, thereby increasing the possibility that buildings may not withstand the rising waters, high winds and earthquakes, causing an increase in the number of persons with disabilities or exacerbating existing disabilities.

Other significant deterrents to accessibility are the poorly designed roads, highways and buildings. Although the law has been changed to ensure that all new government structures, including schools, will have ramps and wheelchair accessible washrooms, there is limited scope for changing existing structures. Further, public transportation facilities have not incorporated any accommodations for use by those with disabilities.

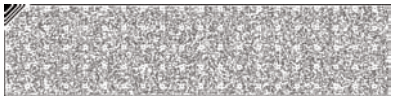
SERVICE DELIVERY MECHANISMS

Disaster relief. In 2010, the Ministry of Food and Disaster Management developed a new matrix, called the National Disaster Response Plan 2010-2015, highlighting the needs of persons with disabilities. This plan provides an outline by which families living with a disability can receive assistance prior to a natural disaster. In addition, the Ministry of Social Welfare and NGOs have developed specific strategies allocating responsibilities to different government departments. Information flyers have been produced to educate disaster relief workers to help them understand the challenges and needs when assisting families living with a disability. It should be mentioned, however, that although the plan specifies the need to assist families with disabilities, it does not include any differentiated strategies for the different disabilities.

Ensuring equal rights. Through the Ministry of Social Welfare in 1999, the semiautonomous National Foundation for Development of the Disabled Persons (Jatio Protibondhi Unnayan Foundation, or JPUF) was created to implement disability-related programmes and services to distribute loans, stipends, grants and other services free-of-cost to persons with disabilities. It also provides free therapy and counseling, runs one-stop service centres, provides devices to increase mobility and functionality (by providing and maintaining various kinds of mobility devices, seeing canes and hearing aids), and maintains a library of resources, such as braille books, internet access, and engages in information dissemination activities. Although starting with a modest annual budget, currently there has been a dramatic increase in both funding and the dissemination of services through a variety of service models. Through Centres for the Assistance and Services of the Disabled (Protibondhi Sheba O Sahajya Kendro), launched in 2009, provisions have been made for free therapeutic services for both children and adults in their communities, and a registration process (and identity cards) is being developed to prevent fraudulence and to ensure that the neediest receive services and funds expeditiously.

EDUCATIONAL AND VOCATIONAL SERVICES

There are no standardized state-provided educational and vocational training programmes for people with disabilities. However, several NGOs have developed unique employment and entrepreneurial training programmes based on local needs. At present, there are integrated schools for those with visual impairments in each of the country's 64 districts, providing services to 640 children.



Under the auspices of JPUF, nearly 8,000 children with disabilities are currently receiving education through 55 special needs schools that are run by two separate NGOs (the Bangladesh Protibondhi Foundation and the Society for Welfare of the Intellectually Disabled).

Currently, the Ministry of Secondary Education is working on a new education policy, which, for the first time, has components to enable the inclusion of children with disabilities in mainstream schools. As test cases, in the 2012 10th grade board exam, five students were given 15 extra minutes to complete the test and also provided with peer assistance for those who needed it. Results showed that those five students earned some of the highest scores nationwide. Despite this success story, whether the inclusion model will be implemented is as yet undecided. The biggest challenge for the inclusion model is minimal teacher training and a lack of necessary professionals to support the schools.

Bangladesh is also challenged by a severe shortage of professionals trained in rehabilitation. Through the Centre for the Rehabilitation of the Paralyzed (CRP), which was established in 1979, and an agreement with Dhaka University, a training programme has been established in order to train physical, occupational and speech and language therapists, as well as various vocational and occupational training for adults with disabilities.

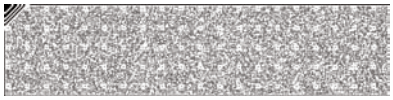
Health care services for persons with disabilities, is sorely challenged in Bangladesh due to inaccessibility. The limited scope for service delivery at the community level for the prevention and reduction of non-communicable diseases, coupled with inadequate service delivery at local levels in many situations, cause or magnify various disabilities. In addition, there is no disability-related or public health training programmes in Bangladesh. One of the biggest challenges for persons with disabilities in Bangladesh results from the allocation of all disability-related issues solely under the Ministry of Social Welfare. This makes it challenging for the Ministry to address the medical, educational and employment needs of persons with disabilities in a comprehensive manner. However, through the establishment of Centre for Neurodevelopment and Autism in Children (CNAC) in the only post graduate medical university in Bangladesh, the Bangabandhu Sheikh Mujib Medical University (BSMMU), an institution under the Ministry of Health and Family Welfare, health professionals and community based health workers are being made aware of the health needs of those with disabilities and given comprehensive training. In order to address the needs of children with disabilities, in 1992, community-based Child Development Centres (Shishu Bikash Kendro) were launched to provide services for those with developmental disabilities and neurological impairments. Multidisciplinary teams of developmental therapists, psychologists, neurophysiologists, and physicians conduct neurodevelopmental screenings and therapeutic interventions at these centres.

FOCUS ON MENTAL HEALTH AND AUTISM

In order to bring greater focus on the needs of children with autism and mental health issues, the Government has partnered with Autism Speaks and the World Health Organization (WHO) and launched the Global Autism Public Health Initiative (GAPH). On 25th July 2011, a landmark international conference was organized in Dhaka that was attended by more than 1000 delegates from 11 countries and four high level dignitaries from regional countries. The conference witnessed the unanimous ratification of the Dhaka Declaration on Autism Spectrum Disorders and Developmental Disabilities and launched the first regional network on ASD (Southeast Asia Autism Network or SAAN). The GAPH Bangladesh Initiative is an innovative, integrated approach that focuses on three areas: enhance awareness, research and services. The tremendous awareness generated by the conference both in Bangladesh and the region has brought the issue of children's mental health and developmental disabilities like autism to the forefront of the public health system in Bangladesh and South East Asia.

A GAPH National Advisory Committee comprised of parents, professionals and government officials composed a Situation Analysis on Neurodevelopmental Disabilities and Autism for the first time in Bangladesh. The Situational Analysis highlights the need for; (1) community awareness and empowerment; (2) research and statistics on the public health burden of autism; (3) training that focuses on building capacity to provide specialized services to individuals with autism and developmental disabilities; (4) greater inter-ministerial convergence and coordination; and (5) standardization and monitoring of services and service providers. In order to address the needs of the community in a comprehensive manner, eight Ministries (Health, Primary and Secondary Education, Social Welfare, Women and Children, Labour and Employment, Finance, and Local and Rural Development) formed a Steering Committee on autism and related disorders and developed a strategic action plan that was formally presented to the President of Bangladesh in July 2012. The main objectives are to facilitate collaboration among local stakeholders, experts, and government officials to develop comprehensive policies and standardized training programmes for those working with persons with neurodevelopmental disabilities.

In 2010 the Ministry launched a community health programme in order to get medical services to the remote rural areas of the country. Community health workers are set to receive training on developmental disabilities in order to implement early screening and intervention. With guidance from the WHO, a training manual on autism spectrum disorders and developmental disabilities was developed specifically for community health workers. This manual is in the process of being launched and content will be incorporated into on-going training modules. This is the first time that medical professionals will be receiving any training on what is typically considered a nonmedical issue in Bangladesh. In addition general



practitioners, pediatricians will also be trained to conduct screenings for developmental delays.

On September 7th 2012, the Ministry introduced a resolution on autism at the 65th annual meeting of WHO-SEARO. Adopted unanimously, this resolution led to the first high-level meeting of ministers for the South Asia Autism Network (SAAN) on 11th February 2013 in New Delhi organized by the Ministry of Health and Family Welfare, India. Attended by ministers of health from Nepal, Indonesia, Timor L'este, Sri Lanka, Thailand, Bhutan, Bangladesh, India and nearly 500 experts from the region, the meeting witnessed the adoption of the Delhi Pledge for SAAN. The meeting afforded government officials and policy makers, as well as local and international autism content experts and stakeholders, to share their strategies and identify partnership and development opportunities among countries across the region. With the goal of enhancing support for individuals, families and communities affected by ASD worldwide, the government of Bangladesh tabled a new UN resolution titled, 'Addressing the Socioeconomic Needs of Individuals, Families and Societies living with Autism Spectrum Disorders and other Developmental Disabilities' (A/RES/67/82) [UN Resolution]. With the support of 71 co-sponsors, the resolution was unanimously adopted on December 12, 2012. The resolution calls for member states to enhance services, increase public and professional awareness of ASD, build research expertise, and promote inclusive education and the full participation of individuals with autism and developmental disabilities in all facets of society. The recommendations highlighted in the Resolution serve as a road map for member states, in addition to international non-governmental and UN agencies, looking to promote the rights and improve the lives of individuals affected by autism.

In addition to the UN adoption, the resolution for 'Comprehensive and Coordinated Efforts for the Management of ASDs', introduced by Bangladesh and co-sponsored by 53 countries, was adopted by the Executive Board of the WHO on May 30, 2013 and will be formally placed at the Sixty-eighth World Health Assembly in 2014. The resolution encourages the implementation of the comprehensive mental health action plan 2013-2020 and the WHA66.9 resolution on disability to scale up care for individuals with autism spectrum disorders and other developmental disorders, as applicable, and as an integrated component of the scale-up of care for all mental health needs.

CHALLENGES AND SOLUTIONS FOR THE FUTURE

Bangladesh, challenged by high population density, natural disasters, political conflict, poverty and low literacy, was one of the first countries to sign both the CRPD and its Optional Protocol in 2007. Despite its commitment to persons with disabilities, current services and programmes lack standardization, inter-agency coordination, quality control mechanisms and standardized training of skilled and semi-skilled professionals. There is a significant lack of data on how many persons are disabled and whether the assistance they are receiving is positively impacting their lives. In addition, no regulatory body exists to either measure the quality of current services or reprimand organizations that fail to meet appropriate standards of care. And, most importantly, families have very limited scope to seek legal action. It is estimated that there are nearly 300 NGOs registered with the Ministry of Social Welfare, yet only 20 per cent of those with disabilities actually receive any support. The country's education system does not have a cohesive and reliable system for identifying and supporting children with disabilities, and no set standards exist for training professionals or paraprofessionals providing services.

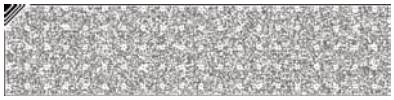
The Government has constituted a National Human Rights Commission under the Ministry of Social Welfare, which is entrusted with the responsibility to act as a watchdog for establishing the rights and fundamental freedoms of all citizens, especially those who are most vulnerable, in order to ensure the rights and privileges of persons with disabilities and to meet the goals of the Disability Welfare Act passed in 2001. The Act has been in the process of being updated for the last two years in order to incorporate and re-categorize mental health and autism.

Other significant impediments to accessibility are the poorly designed roads and buildings. Although the law has been changed to ensure that all new government structures, including schools, will have ramps and wheelchair accessible washrooms, there is limited scope for changing the existing structures. Further, public transportation facilities have not incorporated any accommodations for use by those with disabilities.

CONCLUSION

Despite its many challenges, Bangladesh is now poised to transition from a low income country to a middle income country. There has been significant progress in its economic growth, child and maternal health, and technology infrastructure as indicated by its success in meeting several of the Millennium Development Goals set by the UN. Even so, there is little evidence to indicate whether or not the country is meeting the needs of all, including those with disabilities. In Bangladesh, persons with disabilities are suffering from limited employment and educational opportunities, social discrimination and isolation. Bangladesh's situation is compounded by inadequate financial support, insufficient services, a limited number of trained professionals, and fragmented policies and procedures. For the first time in its history, the government has taken significant steps in developing comprehensive programmes to address these issues without which those with disabilities cannot hope to become active and participating members of society. Until and unless a regulatory body can be created that establishes and monitors a standard of care, persons with disabilities will always remain vulnerable to abuse and exploitation in Bangladesh, especially during conflicts and disasters. ■ ABILITY

routledge.com/books/details/9780415811651





jennifer esposito

Bake Me Happy

Jennifer Esposito made a name for herself with her TV and film work, including *I Still Know What You Did Last Summer*, *Crash* and *Blue Bloods*. But in recent months, she's switched reels to launch her latest passion: Her gluten free bakery, Jennifer's Way, in New York City. There, she creates delicious breads, cookies and other treats to satisfy the tastes-and health-of those with celiac disease. Last spring, she published her book, *Jennifer's Way*, chronicling her own personal struggle with the autoimmune disorder. *ABILITY*'s Lia Martirosyan and Chet Cooper made their way into the bakery as the warm aroma enticed their senses.



Jennifer with fiancé & business partner, Louis Dowler, all smiles in front of their NY bakery

Jennifer Esposito [pointing out her freshly baked goods]: So you have a quinoa bread here. That is a sun butter raspberry muffin. That's a pumpkin chocolate chip. That's a chocolate chunk. That's our jelly donut. That's a cinnamon donut, and that is a jam dot. All this is gluten free, dairy-free, soy-free, egg-free, refined sugar-free, yeast-free.

Cooper: Yes, but is it free?

Esposito: For you it is. (*laughs*)

Cooper: How do you make something gluten free?

Esposito: You take out wheat, rye and/or barley. That's why we use things like quinoa. It has no natural gluten protein.

Cooper: What about the sugar content?

Esposito: We don't use a lot of sugar. We use either honey, maple syrup, or organic, unrefined cane juice. Feel free to taste everything. These have a little bit of sugar because they're more of a cookie and a pastry, but our breads have a teaspoon of honey and no yeast. It's made of chia flour and millet and stuff like that. I came up with these alternatives because I was ill, and didn't want to put in ingredients that I didn't need, or that were empty. So I started using maple syrup because it's a natural antioxidant. Everything had a purpose; it's not just rice flour and tapioca starch. That's not what we do here.

Lia Martirosyan: Are the breads without yeast more of a flatbread?

Esposito: No. You see these big loaves? They're delicious, and you would never know that they don't have yeast. There are lots of different ways of leavening. I had to find them because before this disease I was obsessed with bread. And to think that I was never going to have it again... Coming up with a recipe took years. I would read every book there was on French bread, Italian bread, this bread, that bread, and every book said, "You're never going to make a bread bread without gluten or yeast." And that loaf is proof that that's not true. It's one of our biggest-selling breads.

You see a cupcake or a cookie or a jelly donut and you automatically think, "Oh, I can't do that. That's trouble." But if I tell you what's in it—brown rice, quinoa, amaranth flour or chia—you would never say "no" to those things. We get a lot of little kids who come in here and their moms don't want them to have starch, sugar and preservatives, and we don't put those things in. I try to show people exactly what they're eating.

Cooper: After reading your book, I guess the next thing

would be pizza?

Esposito: I do make pizza.

Martirosyan: Do you add cheese and everything?

Esposito: No. I top it with things like pear, arugula, figs, olive oil and tomatoes. But no cheese. So it's gluten and dairy free because a lot of celiacs cannot have dairy, and they suffer because they really don't want to give that up, either. I haven't really heard of a celiac who can successfully eat cheese or dairy. There's usually some hidden pain involved.

My other career was wonderful, and I still do it from time to time. But this feels like where I'm supposed to be. Everything makes sense. Without having those years behind me, I would have never been able to get this far and get this much attention. People really don't want to talk about this subject in a serious manner, for whatever reason. But you're screwing with something that's very, very sacred to people: their food, how they eat, and how they live.

Cooper: From your book, I could feel your pain. You said, "I feel bad—"

Esposito: "—when I eat this," right. My symptoms were so all over the map. There are 300 symptoms with this disease.

Cooper: That many?

Esposito: And that's the thing, you may not know that your symptom is connected to the disease. I'd eat something, and it would make my headache go away, but then my stomach would hurt. So even if I did start to connect the dots in the stomach area—not eating carbohydrates and feeling less bloated—I would still get sinus headaches, because symptoms are not going to instantly go away just because you stopped eating gluten. I had so much damage throughout the years that even after a year without it, I was still going through detox.

Martirosyan: When you were going through the early stages of testing, doctors never checked for an autoimmune disease?

Esposito: No, never.

Martirosyan: Do you know if it always shows up as an autoimmune weakness?

Esposito: I don't know what specific tests they took, because it's been so many years, and I wasn't as knowledgeable as I am now. The usual blood test is for allergies that will cause anaphylactic shock. There's another blood test that looks at what happens when allergens in food hit the gut. That's where things show up like, "Oh, you're allergic to this, this and this." I never had that. Maybe that would have shown I had gluten intolerance.

They did test me for Multiple Sclerosis at one point, and also ruled out lupus, so I guess they were looking at certain autoimmune diseases, but then my blood work would come back fine. What was showing up, over the previous 10 years, was a tricky liver enzyme. They always wrote it off as an infection somewhere, never thinking that it had something to do with toxins in my body that weren't getting released. I don't look at the doctors and feel like they did me wrong; I understand that my symptoms were all over the place. But there needs to be more attention paid to the individual person, rather than looking at a chart and saying, "You don't fall into this category or this category or this category."

Cooper: Especially given that there are 300 different symptoms.

Esposito: Yes, and people get used to living in pain. I used to live uncomfortably, fearfully, because of panic attacks, and the anxiety was constant. I saw my mother live that way; she saw her mother live that way. My grandmother died of colon cancer, so I was used to seeing nervous people. But people get used to just taking a pill.

Cooper: I lived in pain for years, but finally got a divorce.

*(*laughter*)*

Esposito: You had to do it!

Martirosyan: Did you ever have Intravenous Immunoglobulin (IVIG) Therapy?

Esposito: No. I have not. My doctor's spoken about that, but I have not. I look into everything because like I said, I still deal with it.

Cooper: Lia has some background in what we're talking about; she's been all over the world and nobody knows what she has.

Esposito: Really!

Martirosyan: Yes, I have symptoms all over the place. But a few years ago, celiac disease came up, and they were going to do an endoscopy—until they told me it would screw with my vocal cords.

Cooper: She sings opera.

Martirosyan: So it wasn't safe for me to do that procedure, and I didn't follow up. And then I read that part of your book about your finding a lump on your neck and your brittle nails. A lump was one of the first things I noticed, and they wrote it off as a virus or my being sick, but I'd never been sick in my life when this all started.







Don Cheadle and Jennifer on the set of *Crash*

Esposito: I would absolutely check out celiac disease. I saw a woman walk in here on crutches. Her hands were like this. [balled up] She had difficulty speaking. They said she had MS, and she was on medication. Turns out she went to this doctor, and she had celiac disease, through her diet, she started to reverse that. Now her hands can open up.

Martirosyan: That's interesting.

Cooper: Does gluten have any friends?

(*laughter)*

Esposito: Seriously. Gluten—especially for people with autoimmune disease—is glue, basically. It holds bread together; it holds pasta together. It's a binder. That's why you see it in a lot of things like makeup and toothpaste. But we can't really digest that in our systems. We don't have the enzymes to break it down, so it sticks. For me, if I eat a piece of gluten, I know it instantly, because it feels like liquid cement in my throat. That's what it's doing in the body, and then it creates inflammation, and inflammation causes disease. Same thing with dairy.

Martirosyan: I read that you shouldn't cut it out, though, until you get tested.

Esposito: In my opinion, if you're suffering stop eating it, and see if you feel better. If you have celiac disease, you have damage in your gut. It may not heal in a week, two months, even up to a year—and even then it sometimes doesn't heal that quickly. I don't want people suffering any longer. And sometimes I've heard where people are off of gluten and they feel better, but they want to get a proper diagnosis, so they have to eat it and then they're in hell. In an endoscopy, they use an instrument to take a biopsy of your intestines.

Martirosyan: Do you think blood tests would be more accurate?

Esposito: Blood tests are not always accurate.

Martirosyan: So you had the endoscopy?

Esposito: I had both.

Martirosyan: Did you feel any soreness?

Esposito: I didn't. I think it's got to be done correctly, when they take a biopsy of the small intestine they shouldn't just go down and take one piece, because the villi may be intact in that place.

[Inflammation from celiac damages villi, which are small, finger-like projections that line the small intestine

and provide a greatly increased surface area to absorb nutrients. In celiac disease, the villi become shortened and flatten out; intestinal damage causes diarrhea and poor absorption of nutrients, which may lead to weight loss.]

So they need to really take a thorough biopsy. I've heard many people tell horror stories about getting an endoscopy, where they take one biopsy and say, "You're fine," and then two years go by and they aren't fine. They have celiac, but the biopsy wasn't done correctly. With me, there were times when I couldn't walk. My knees would give out completely. And if I get any kind of gluten, that's exactly where it hits, my knees. I can't walk. A young girl I know, her mom brought her here. She was 15, having problems, problems, problems. Didn't know what it was. One day, I saw it in her face, and then she just fell. They brought the ambulance, the doctor, and they said, "She's got palsy in her face?" It happens sometimes. Turns out she had undiagnosed celiac disease that was causing so much inflammation that her brain was swelling. They had to open up her skull, release the pressure on the brain. She had to relearn how to talk.

Martirosyan: Destroys everything.

Esposito: Exactly. This is a real issue because your insurance company will cover a generic drug, and sometimes they're not gluten free. So I'm paying out of pocket to get a name-brand drug, and I can't tell you how many times they didn't have it. I went to the hospital recently because I had some kind of allergy, and my face started to blow up a little. They wanted to put me on a steroid that I've taken before. By the end of that cycle, I had to have a steroid and an antibiotic, which cost me $1,700 for the name-brand drug. Generic drugs, that's the next hurdle and it's enormous.

Cooper: Are you saying the pharmaceutical companies won't tell you—

Esposito: —if it's gluten free. But their version of gluten free and what a celiac calls gluten free are very different. That's why every restaurant, every product says, "gluten free," and then you start asking questions, and you realize, unless that product was done in a separate area, it is not completely gluten free. You cannot guarantee there's no cross-contamination if you're using the same line to make a wheat-derived pill.

Martirosyan: How long have you been off gluten?

Esposito: Probably five years now. Now I'm a functioning human being. I wasn't functioning towards the later years, when I finally got diagnosed. Now I'm functioning in a big way. But I also went 30-something years without a diagnosis, so the longer you go, the more damage there is.

Martirosyan: I'm thinking about the woman you mentioned with the dexterity issues who was diagnosed with MS. The fact that you say her fingers are straightening out is a huge deal because it's rare to impossible to reverse atrophy.

Esposito: Huge. She was in a wheelchair, and she's walking on these crutches now. But she sat here and clearly told me, "I'm doing so much better, but I cheat sometimes." But you just can't cheat. Not safely.

Martirosyan: I figure if you have a solid diagnosis, and you're feeling bad why play around?

Esposito: I don't understand it either, but it's a hard thing to switch in your mind, because food is a basic need, basic fun, basic social aspect of life.

Martirosyan: There was a time, I tried going vegan, which was kind of unheard of, because there weren't many options out there. I was doing more lentils and beans. I lasted six months. So what's the difference between vegan and gluten free?

Esposito: Vegan is taking away any animal products. What we're doing is taking away the gluten that's in breads, pastas, cookies. With a vegan diet you can eat bread and pasta and all that stuff. It's a completely different thing. That's why when I went vegan for a while—because I tried every diet under the sun—I would feel a better, but then it wouldn't last because I was still having pasta and bread. Though I was eating a ton of vegetables and all this other great stuff. These days, they pump so much stuff into our food to grow it quicker, keep it on shelves longer, make it fluffier… So the natural gluten that was in these products is no longer being able to just be what it naturally is. Things have become so over processed that we can't function any more.

Cooper: So your place in all of this seems to be to create breads, cakes, and tastey desserts?

Esposito: I always tell people this. These are the things that you absolutely cannot have out in the world: You can't have bread, a cookie, pasta. But occurring in life is beautiful naturally gluten free food. You should be eating that fish, vegetables, meat, beans. Those are all naturally gluten free. Again, if it's processed, then it could be added. But naturally gluten free foods are everywhere.

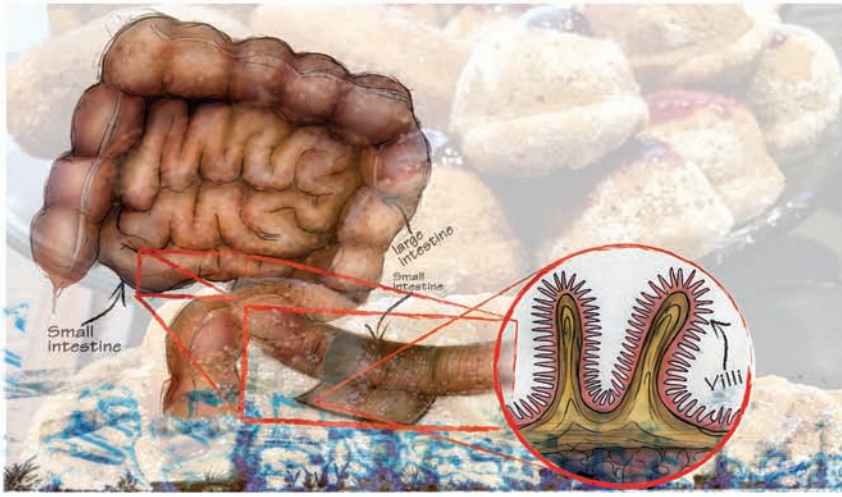
Cooper: So you found this is what was missing?

Esposito: Yes. Before this, we weren't baking with quinoa, chia and amaranth flour. They're not light and fluffy, and they can be tricky to bake with. These are different flours and grains that people weren't using before. There's a difference.









The mouth-watering goodies described in the beginning. A before & after shot, would be cruel. So we didn't.

Martirosyan: Are you bringing in bakers and training them?

Esposito: Yes, but I like to get people who don't have a ton of experience.

Cooper: Do you think teaching from scratch might be better than trying to retrain people?

Esposito: Yes, because they're open. Like a French pastry chef I trained; she was waiting for the bread dough to act like regular dough, and it wasn't going to do that.

Cooper: Now you're starting to ship your products?

Esposito: We started recently. We have a facility in Queens that's about 13,000 square feet. We started manufacturing the cookies there. It's not only gluten free, but also nut free. We're in the process of changing this place over to nut free. We're already peanut free here, but we use a few nuts. We want to remove every possible allergen. I don't want to leave anyone out, because I know how horrible it is not be able to eat freely.

Martirosyan: What are you doing about shelf life?

Esposito: We have no preservatives. We have a food scientist who's one of our partners now. It's a different way of baking it, a different way of adding certain ingredients. It's been amazing to see, because just the way he bakes things, they ship better and last longer. I want to be able to get the food to everyone who wants it. I received so many wonderful emails thanking me, but this one really touched me: The mom of this 4-year-old girl said, "She's a celiac, can't have this, can't have that." But the girl was sitting there eating one of my cookies with a big smile on her face.

Cooper: Have you thought about opening bakeries around the country?

Esposito: I would love to because there is a difference with what you get here, and what you get after it's been shipped.

Martirosyan: Hopefully LA is your next destination.

Esposito: I would love it. A lot of people ask about our coming to LA, and they ask about our going overseas, like England.

Martirosyan: I can open up my garage to you. It's very spacious.

Esposito: *(laughs)* Perfect! We'll take it! I can make anything work at this point. This place used to be a hair salon.

Cooper: There's still a lot of education that's needed. We were just at an event and happened to speak to a nutritionist; we mentioned celiac and she rolled her eyes as if it were a fad. But then it turns out her friend has it. She seemed confused.

Esposito: When you don't know enough about something, you'll roll your eyes and try to brush it off as the other person's problem, not something that you need to adjust. It's very sad. That happens a lot. Experiences like those pushed me to write my book... And then I realized that I really wanted to figure this out for myself. I can't give a definite answer about what's going to help you, but I can absolutely give you a whole bunch of different answers as to what's going on and why you should look into this, this, and this. A woman wrote to me: "I'm a nurse, and I learned more from your book than I have about this disease in any class from any doctor." There are so many things that lead back to that underlying issue with those symptoms. Don't just look at the symptoms. "I'm tired, let me drink coffee. Let me have a Red Bull." You need to ask yourself why are you tired?

Cooper: Because you didn't have enough Red Bull.

(*laughter*)

Cooper: As I'm reading the book, one thing I could not understand, and maybe I just don't know you well enough, but how did you not gain a bunch of weight. It seems like you ate a lot.

Esposito: I did. I still do.

Cooper: Were you obese?

Esposito: No. I did go through points in my life when the wheat weight would stick on and then it wouldn't. I was always a very active kid. I was in gymnastics, running. And then I would hit lows where I was so exhausted that I couldn't move. I really believe that my body was not being fed. You have two versions of celiac disease where you either gain an extreme amount of weight because of inflammation, or you're extremely underweight. Some children almost die, because the body is not absorbing nutrients. I have a friend of 25 years who's 6-foot-5, and we would go to brunch together, and I would eat him under the table. He'd look at me like, "What is wrong with you? How on earth are you doing this?" I wasn't full. I never felt satiated, because I was lacking God knows how many nutrients at the time.

Cooper: There's part of the book where you talk about how your mother had to feed you with two spoons.

(*laughter*)

Esposito: Oh, yeah, she used one and say, "Here comes the plane." I was like, "Feed me!" And as soon as she took out the first spoon, it was like, "Agh!" and she'd have to come with the other one. So she'd be shoveling the food in.

Cooper: And your fiancé does the same thing?

Esposito: Yes.

(*laughter*)

We enjoy that. It's a little game we play. You don't want to invite us over.

Martirosyan: First one at the Thanksgiving table, last one to leave?

Esposito: Oh, yeah. And now I make the Thanksgiving meal so I can eat everything there. And I do. I love food. Looking back, I would have definitely gone to culinary school. There was a time where I almost quit acting to go to culinary school. It was really, really close. It was such a change of life. I was like, "Really? Should I?" I wish I would have, because I can't go now, because I can't taste everything.

Cooper: Maybe you should open up a school.

Esposito: That would be amazing, because I know a lot of young people who do have this disease. My goal is to have a farm and be able to grow food; I have organic tomato and basil plants on my ledge in Brooklyn, indoors, up against the window! And I had three tomatoes this weekend from that little plant. I was thrilled. I have a picture of it. They're beautiful. They're delicious. And you don't even taste tomatoes like that any more in stores. That's my goal, to be able to have a farm, a garden, and be able to pick my own vegetables.

I think that's why our products do so well, because people want an option, whether they're celiac, autoimmune, gluten intolerant. They want this product because it's clean and there's nothing in it that you can't pronounce. Nothing.

Martirosyan: You're Italian, both sides?

Esposito: Both sides.

Martirosyan: Were you born there?

Esposito: No but I've been many times. I love it there. I would love to have a farm there.

Martirosyan: Speaking of which, wine. Is that gluten free?

Esposito: It is gluten free, thank Jesus.

(*laughter*) ■



Spaghetti Squash, Kale, and Tomato SERVES 4

This delicious recipe is so great that you won't miss spaghetti made with wheat. I like steaming the squash, but you can also roast it if you prefer.

1 medium spaghetti squash
1/2 onion, chopped
11/2 cups cherry tomatoes
2 cups chopped kale
1/2 cup olive oil, divided
1/3 cup Daiya non-dairy cheese alternative (or dairy cheese, if you prefer and can tolerate it)
11/2 teaspoons salt Black pepper to taste

Bring a large pot of water to a boil and place a steamer tray inside. Carefully cut open the spaghetti squash and clean out its seeds. Place the squash halves on the steamer tray, cover the pot with a lid, and steam squash for 30-40 minutes, or until a fork is able to go through it.

While the squash is cooking, add 4 tablespoons of the olive oil to a pan over medium heat. Sauté onions until clear, then add cherry tomatoes. Add salt and pepper. When tomatoes start to get soft, squish some of them down to get the juices out, but leave some whole. Sauté for 10 minutes, stirring occasionally. Add kale and the remainder of the olive oil.
When the kale starts to cook down, which will take just a few minutes, lower heat to medium-low, to bring the mixture down to a simmer. When the squash is done and cool enough to handle, use a fork to scrape the flesh out of the skin in a downward motion to get spaghetti-like strands. Transfer all spaghetti squash into a bowl and combine the kale and tomato mixture.

Before serving, top with cheese, more salt and pepper to taste, and even some more olive oil, if you like.

Sesame Parsnip Fries SERVES 2-4

What I love about this recipe is that it turns parsnips into exact replicas of the glorious fry.

Parsnips are rich in potassium and a good source of daily fiber. They also store very well, up to 2-3 weeks unwashed in the refrigerator (in a plastic bag). Although autumn is their peak season, they're available year-round, and it's best to choose ones that are moderate in size and well-shaped-not pitted or shriveled. Sunflower butter-ground up sunflower seeds-is the surprise ingredient here. It creates a savory, crunchy coating. Delicious!

2-3 medium-size parsnips
3 tablespoons sunflower butter
21/2 tablespoons sesame seeds
2 teaspoons organic olive oil
1/2 teaspoon salt

Preheat oven to 400 degrees and line a baking sheet with parchment paper. Clean parsnips and peel outer layer like a carrot. Cut parsnips into thin strips like fries. In a large bowl, combine sunflower butter, sesame seeds, olive oil, and salt. Add parsnips and mix with a spoon or your hands until the strips are coated. Place parsnips on the baking sheet and bake for 35-50 minutes, or until crispy and brown.

Sweet Potato Scones MAKES ABOUT 36 SCONES

Maple sugar has antioxidant properties and you can sub it in equal amounts for regular sugar. If you can't find maple sugar, you can use coconut sugar, date sugar, or even brown sugar, but those have much lower antioxidant and nutrient values.

1 cup sweet potato puree (bake and mash a sweet potato, or use 1/2 of a 15-ounce can sweet potato puree)
3/4 cup rice milk (or milk of choice)
1/3 cup grape-seed oil 1 tablespoon fresh lemon juice
11/2 cup almond flour
1/2 cup arrowroot starch
1/2 cup brown rice flour
1/2 cup quinoa flour
1/2 cup chopped pecans (optional)



1/3 cup maple sugar
2 tablespoons baking powder
1 teaspoon cinnamon
3/4 teaspoon xanthan gum
1/2 teaspoon fresh dried vanilla (or 1 teaspoon liquid vanilla)
1/4 teaspoon ground cloves
1/4 teaspoon salt
1/3 cup maple syrup (for brushing on top of scones)

Preheat oven to 400 degrees F and line a baking sheet with parchment paper. Whisk together the sweet potato, rice milk, oil, and lemon juice (if using liquid vanilla, add here). In a separate bowl, combine almond flour, arrow-root starch, brown rice flour, quinoa flour, pecans (if you're using them), maple sugar, baking powder, cinnamon, xanthan gum, dried vanilla, cloves, and salt. Whisk out lumps. Add the wet ingredients to the dry and combine with a wooden spoon. Take a heaping tablespoon of batter and drop on the baking sheet. Place in the oven for about 15-17 minutes (longer if you want firm texture and/or slightly browned bottoms). After about 11 minutes, or when the tops of the scones get a bit firm, brush maple syrup over the tops and then continue to bake. These scones will keep in an airtight container or Ziploc bag for at least a couple of days, or up to a week in the refrigerator

Oatmeal Raisin Cookies MAKES ABOUT 36 COOKIES

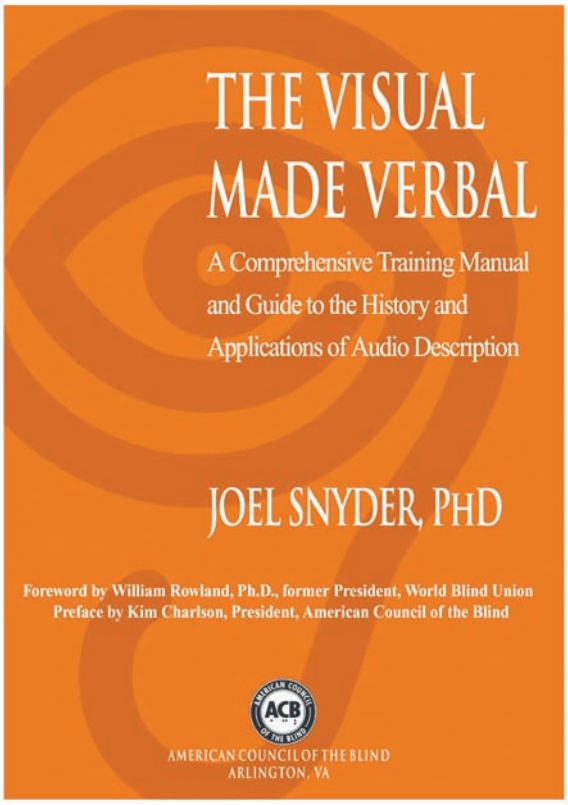
For this recipe, it is absolutely crucial to use certified gluten-free oats, because other oats contain gluten. I was able to have oats later in my journey, but not in the beginning, so you'll want to be sure you can tolerate oats before you make these-not everyone can. The duration of the baking depends on how crispy you like your cookie.
3 cups certified gluten-free oats (important that the packaged is marked as gluten-free!)

1 cup brown rice flour
1/2 cup maple sugar, date sugar, or coconut sugar
1/4 cup arrowroot starch
1/4 cup sorghum flour 1 teaspoon cinnamon
1/2 teaspoon baking powder
1/2 teaspoon baking soda
1/2 teaspoon salt
1/2 teaspoon xanthan gum
1/2 cup maple syrup
1/2 cup grape seed oil
1/3 cup applesauce (no sugar added) 3/4 cup raisins

Preheat your oven to 375 degrees F and line a baking sheet with parchment paper. In a mixing bowl, combine the oats, brown rice flour, sugar, arrowroot starch, sorghum flour, cinnamon, baking powder, baking soda, salt, and xanthan gum. In a separate bowl, combine the maple syrup, grape-seed oil, and applesauce. Using a wooden spoon, slowly mix the wet ingredients into the dry a little bit at a time. When dough is thoroughly combined, add raisins. Place tablespoon-sized pieces of dough on the baking sheet and bake for 15-25 minutes. These cookies will last about a week stored in an airtight container in the refrigerator. ■ ABILITY

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AN EXCERPT FROM



AUDIO DESCRIPTION - WHAT IS IT?

Audio Description (AD) makes the visual images of theater, media and visual art accessible for people who are blind or have low vision. Using words that are succinct, vivid, and imaginative (via the use of similes or comparisons), describers convey the visual image that is either inaccessible or only partially accessible to a segment of the population. In addition, the visual image is often not fully realized by people who see, but who may not observe. Description may also benefit people who prefer to acquire information primarily by auditory means and those who are limited—by proximity or technology, for instance—to accessing audio of an event or production. While description was developed for people who are blind or visually impaired, many others may also benefit from description's concise, objective "translation" of the key visual components of various art genres and social settings.

I believe that Audio Description is a literary art form in itself. It's a type of poetry—a haiku. It provides a verbal version of the visual—the visual is made verbal, aural (he points to his ear) and oral (he points to his mouth). A haiku because describers must use as few words as possible to convey that visual image for the benefit of people—all people, including children—who are blind or have low vision. Audio Description is an "Assistive Technology"; it is meant to enhance, not replace the user's own powers of observation.

In some ways, for an access technique/form of audiovisual translation that is over 30 years old as a formal practice or area of inquiry, a great deal of progress has been made. Most notably in the U.K., where a mandate exists (albeit relatively modest) for description on broadcast television, significant strides have been made in developing the state of this art, for media, in performance (including sporting engagements), and for exhibitions.

But as far as the actual practice of audio description, other countries fall far behind, including my own United States, the birthplace of the technique. It is noteworthy too that practically all research in this field originates in Europe where description is considered a form of translation and studied as such. An informal survey of American graduate programs reveals no "homes" for advance study of audio description.

Bernd Benecke (2004: 78) notes that audio description is "as old as sighted people telling visually impaired people about visual events happening in the world around them." Pujol and Orero (2007: 49-60) add an interesting twist on that perspective: "While it is true that research in the field has just started, with no PhD to date, we believe we should take into consideration the many studies and range of experience which already exists, since this may shed some light on the topic and further the insight of new research." They cite "ekphrasis" (or "ecphrasis"), " a literary figure that provides the graphic and often dramatic description of a painting, a relief or other work of art. This rhetorical phenomenon is common in the epic poems of Ancient Greece." In Michael Dirda's Washington *Post* review of Leonard Barkan's *Mute Poetry, Speaking Pictures*, he presents Barkan's definition of ekphrasis as "the verbal presentation of an object of a visual object inside a literary work." Indeed Dirda notes that Barkan's title derives "from an ancient saying credited to Simonides of Ceos: 'Painting is mute poetry, poetry a speaking picture.'" Dirda continues: "Think of Homer's description of the elaborately tooled shield of Achilles in *The Iliad*." A portion of Homer's work follows:

"Then first he form'd the immense and solid shield;
Rich various artifice emblazed the field;
Its utmost verge a threefold circle bound;
A silver chain suspends the massy round;
Five ample plates the broad expanse compose,
And godlike labours on the surface rose.
There shone the image of the master-mind:
There earth, there heaven, there ocean he design'd;
The unwearied sun, the moon completely round;
The starry lights that heaven's high convex crown'd;
The Pleiads, Hyads, with the northern team;
And great Orion's more refulgent beam;
To which, around the axle of the sky,
The Bear, revolving, points his golden eye,
Still shines exalted on the ethereal plain,
Nor bathes his blazing forehead in the main."

I have noted that audio description as a formal process of

translation and accessibility is just over 30 years old-if one counts as its genesis in the literature as the landmark 1978 Masters thesis by Gregory T. Frazier, The *Autobiography of Miss Jane Pittman: An All-audio Adaptation of the Teleplay for the Blind and Visually Handicapped*.

Since that time, the vast bulk of serious study of audio description has been in Europe as a form of "audio-visual translation." The field of study derives from/relates to a focus on subtitles for video and film. With the majority of commercial media originating in the United States of America, in English, access to this work for speakers of other languages happens via subtitling or dubbing. Audio description represents another kind of "translation" in media—from visual images to words for the benefit of those who have no access to the visual image. Unlike most "light dependent" people, people who are blind or have low vision speak a language that is not dependent on the visual. Consequently, audio description has been embraced as a new field of study in academic programs that encourage the exploration of audio—visual translation.

So audio description can no longer be considered in its infancy—perhaps it is in its adolescence, with new techniques on the horizon, aesthetic innovations incorporating description within the material it supports, and broadened access to new media and varied settings for increased numbers of people who are blind or have low vision.

AUDIO DESCRIPTION - WHO'S IT FOR: ATTITUDES ARE THE REAL DISABILITY

Who Are "The Blind"? They are *not* "the blind." They are individuals—housewives, scientists, artists, business people. They are you—or me—at some point in our lives.

The American Foundation for the Blind reports that 21.2 million Americans have vision loss; in 2007, Nigeria's Minister of Health reported that the number of people who are blind worldwide is likely to increase to 75 million by the year 2020. While description was developed for people who are blind or visually impaired, many others may also benefit from description's concise, objective "translation" of the key visual components of various art genres and social settings. Audio Description is an "assistive technology"; it is meant to enhance, not replace the user's own powers of observation.

Disability is indiscriminate and universal—and the responsibility of us all. It demands attention from us regardless of race, age, size, gender. "The blind" don't exist. They are unique individuals living with some degree of vision loss as the result of a wide range of causes. Most users of description are not totally blind; indeed, only 1-2% of the legally blind are congenitally blind (blind from birth); others are adventitiously blind or developed total blindness later in life. Most at one point had all or some of their sight and now they may have only peripheral vision, they may see only shapes, light and dark, colors, movement, shadows, blurs, or "blobs"—or have "tunnel vision." Only 10% know Braille.

A true story: a blind fellow visiting a museum with some friends was once asked, "Excuse me, but what you doing in a museum? You can't see any of the exhibits." His response? "I'm here for the same reason anyone goes to a museum. I want to learn, I want to know and be a part of our culture." His inability to see shouldn't deny him access to our culture and I believe it the responsibility of our arts institutions to be as inclusive as possible. Cultural access is everyone's right. There simply is no good reason why a person with a particular disability must also be culturally disadvantaged.

The person that confronted that gentleman in the museum—along with too many organization staff members-have a serious disability: they're "attitude impaired." Indeed, I often wear a pin that reads "Attitudes are the Real Disability." We all need to understand that notion, particularly when encountering someone who perceives the world in a different way. Being blind is less about the loss of sight and more about perceiving the world in new ways-ways which are not dependent on light. And they are people with a wide range of *abilities*: there are blind skiers, blind photographers, blind visual artists, blind bowlers, blind attorneys, blind restaurateurs (see a review of "Blindekuh" or "The Blind Cow"—Note: I've dined at The Blind Cow in Zurich and the food is… "indescribably" delicious!)… and the list could go on.

In June 2013, a "day of solidarity with the blind and visually impaired community" was established in Israel (June 6). A blogger for *Haaretz*, Neta Alexander, writes of a blind marathon runner she interviewed. She asked him what other hobbies he has, besides running. She was surprised by his response: "I love the cinemas. I go almost every week.… I go with a companion and he fills in details that are very valuable to understanding the plot.… But I especially love the thrill that I feel from the audience. When I'm with a lot of people, I actually can feel when they are going to laugh or when they react with excitement. I experience the film through their feelings.

Ms. Alexander continues: "In one event on the Israeli "Blind Day," the Tel Aviv Cinematheque will allow the audience to experience a movie as blind people experience it: the film *Proof* will be screened and sighted people will get a blindfold and headphones through which they will hear not only the sounds of the film, but also description of what is happening on the screen.… If you ask yourself why the hell you should try and experience a movie for an hour and a half without seeing it, the answer is quite simple: the event is not only a gesture of solidarity with the blind, but can extend our sensory perception of the world which consists of—unfortunately—almost total reliance on the sense of sight. In fact, the

digital culture we live in is so visual, it is hard for us to imagine we could ever live differently.

But in early societies, for example, there were communities that were based on oral tradition; traditions passed orally from generation to generation. Humans relied on memory, learned to memorize complex mythologies with dozens of characters and numerous events. Before the invention of writing our ears were as dominant as our eyes, as were the senses of smell and taste, which allowed people to identify hazards.… Life in a visually-oriented society completely changed the way our brain works: from the loss of the ability to memorize phone numbers (not to mention texts, songs and speeches) to our virtual addiction to visual stimuli."

Avraham Rabby (born blind) writing in *The Jerusalem Post* of Israel's day of solidarity with the blind and visually impaired community, provides an important alternative perspective: "On that day, you will be able to participate in numerous events supposedly aimed at raising your awareness of the nature of blindness, of how blind people live their daily lives and of what problems they face.… At the Knesset, some Knesset members will be called upon to blindfold themselves and compete against a team of blind athletes in a game of 'goal-ball,' a sport specially designed for the blind. At other venues, people will be invited to perform everyday tasks, such as eating at a restaurant and shopping for groceries, with their eyes closed or in a totally dark environment."

But Rabby has concerns with this approach to "awareness": "All the blindness-simulation exercises on the Blind Day schedule are gimmicks which assume that the principal problem facing blind people is the actual loss of sight.… [But] the Knesset members who will blindfold themselves and attempt to play goal-ball will never function as practiced blind people do. As soon as they don their blindfolds, they will be virtually paralyzed by fear for their physical safety and exasperated by their inability to perform the simplest of tasks as they did with their eyes open. They will be totally disoriented on the goal-ball court while their blind opponents run rings around them, and their self-confidence will be at zero. As a result, rather than raising the Knesset members' awareness of the true nature of blindness, this experience will reinforce whatever stereotypes and prejudicial notions they may have had about the helplessness and incapacity of blind people."

Unfortunately, what will remain is the real problem facing blind people: "not so much the physical loss of sight but the low expectations the sighted society has of us and the discrimination we constantly encounter."

Rabby's conclusion is that "Blind Day should be used… to compel the Ministry of Education to provide [students] with Braille and recorded textbooks ...to highlight the fact that blind 18-year-olds [are exempt] from mandatory military service, even though… if they insist on serving, only permits them to enlist as volunteers… to protest [the] failure to install voice announcements of bus numbers and routes on all buses and at all bus stops… to [convince people] of the abilities of the blind [with] live demonstrations of blind people at work, competently performing a wide variety of jobs, including jobs with high-level professional and managerial responsibility."

Let's turn it all on its head: can sight be a "liability"? In his book, *An Anthropologist On Mars*, Oliver Sacks' fourth tale, "To See and Not See," is about partially restored sight and how it was not a blessing. This story illustrates how sight is learned from infancy and is largely a constructive and interpretive function of the brain. A man, aged 55, has been blind since age 5. He regains partial vision but is no longer able to walk: his distance perception is skewed and he stumbles over shadows. Eventually, gradually, his vision deteriorates again. This story, based on the experience of one of Sacks' patients, lets us see how the world of the sightless can be rich and fulfilling beyond our imagination.

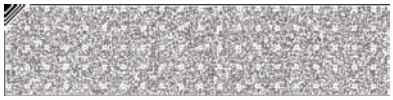
In the same vein, Brian Friel's play *Molly Sweeney* depicts a woman who is blind and is presented with the possibility of a cure. Her husband, Frank Sweeney, cries "If there is chance, any chance, that she might be able to see, we must take, mustn't we? She has nothing to lose, has she? What has she to lose? Nothing! Nothing!" The play makes evident that Frank Sweeney devalues the life his wife has led as a blind woman. The program notes for the Arena Stage production of the play suggest that "He, like most people, think the blind have been cheated out of living life to the fullest, and at best, can only be pitied.… studies indicate that the sighted know almost nothing about the blind. They are frequently astonished when the blind demonstrate any level of competence.… They cannot comprehend that the blind may be perfectly content to remain so.… The more informed are likely to treat a blind person with more respect."

Still, many people have never met a person who is blind. He/she is A PERSON first-with low or no vision and a wide range of abilities. We must strive to "See the person not the disability."

AUDIO DESCRIPTION - WHAT'S NEXT?

What are the specific areas where audio description holds promise for future development? In no particular order, I see a range of opportunities. Let me "describe" them:

- "Self-description": No, I'm not speaking of describing one's self! In schools, including higher education, in employment settings, and at conferences, description is most efficiently provided by the speaker making a presentation. "Describe as you go" is the key, not necessarily assuming that all in an audience have easy access to the images being presented. It's common for speakers to ask: "Can everyone hear me?" But can everyone see the





images in your PowerPoint or in a short video? At best, a presentation without description is insensitive to an audience's needs; at worst, the situation results in an embarrassing episode similar to that which occurred at VISION 2008 in Canada cited earlier.

- Video Description Research and Development Center (VDRDC) Supported by the U.S. Department of Education, the VDRDC "investigates innovative technologies and techniques for making online video more accessible to blind and visually-impaired students and consumers. Through collaboration with a broad array of partners and stakeholders in the Description Leadership Network we are developing advanced video annotation methods for use in a wide variety of educational settings, as well as helping educators and other description providers make better use of the tools already available." I served as a member of the Description Leadership Network.

A key project of the VDRDC is its Descriptive Video Exchange (DVX), a set of web-based tools that enable anyone to create, access, and share video description content from anywhere video is being streamed or played—also dubbed "You Describe." While I am an unwavering advocate for the highest quality in description, a mechanism for encouraging all people to become familiar with description by doing description can only help build awareness of a relatively new access technique.

- Visibility: As I craft these notes, I pause to follow the television coverage of the 2013 Memorial Day ceremonies in the United States. An army sergeant performed a stirring rendition of "America, The Beautiful"—accompanied by a sign language interpreter. All people see the interpreter and are reminded of the importance of making the words being sung accessible to people who are deaf. And yet my own description of the presidential inaugurations for ABC-TV in 2009 and 2013 was heard only by those who accessed a separate audio channel. Similarly, at a performing arts event, description is accessed only by those who desire the service.

And that's how it should be. But the result is that audio description is "invisible." I believe that to a great extent the future of audio description is tied to its visibility among consumers as well as the general public. We need to create more effective PSAs (Public Service Anouncements), perhaps in association with the public sector—and it is critical that advocates for audio description collaborate with other constituencies—people who are deaf, people with learning disabilities, people learning English, all people who can benefit from the development of audio description.

- Information: As a member of the Federal Communications Commission (FCC) Video Programming Accessibility Advisory Committee (VPAAC), I advocated for the widest possible distribution of information regarding: a) what description is available on public broadcast television; and

b) how to access the AD feeds. The committee's final report notes "the importance of making widely available information about what programs are video described …(that) entities required to provide described programming… must also provide information about described programs on their websites, provide this information to programming information distributors such as Rovi and Tribune Media Services, and consider alternative ways of ensuring that blind and visually impaired consumers have access to such information…(that) networks should provide information on their web sites indicating which programs they are airing with video description. To ensure that the information can be accessed, it must be provided in a manner that is accessible to and usable by individuals who are blind or have a visual impairment (and that) information regarding programs with video description be made accessible, usable, and searchable online and through other means such as by telephone using an automated Integrated Voice Response (IVR) system."

In addition, the American Council of the Blind (through its Audio Description Project), the Royal National Institute of Blind People, and Canada's Accessible Media, Inc. maintain excellent repositories of information on audio description in a wide range of genres:

- Quality: It is my hope that this volume will contribute to more audio description world-wide and audio description that is of the highest quality. Guidelines have been established in a number of countries—and this volume is informed by many of them—but I believe that a "guideline of guidelines" developed with significant input from and endorsement by users of description could be an important advance for the field. Rick Boggs, of The Accessible Planet and Audio Eyes, is a long-time advocate of more—and more informed—inclusion of description consumers in the development of guidelines and, as importantly, the involvement of description consumers in the production of audio description—as consultants, audio editors, voice talent and in other capacities. He offers workshops focused on audio description skills for consumers of audio description.

It is my hope that in the coming years a national certification program can be established for the review of individuals and companies who offer audio description professionally and trainers of describers, similar, perhaps, to the program established in the U.K. for describers in the performing arts.

- New Developments: Two prospects on the horizon warrant special note:

Ryerson University—Deborah Fels, PhD: When I coordinated funding for multidisciplinary categories at the National Endowment for the Arts, I developed guidelines language that invited applications for funding of access projects that represented aesthetic innovation. In the same vein, Deborah Fels of Ryerson University in Canada posits that "Accessibility can be entertaining." The Ryerson website notes that "Video description and closed captioning (can be) an integral part of the creative process." Quoting Dr. Fels, it goes on: "Normally this work is done by a third party after the film is complete. We are working with the creative team to write these tracks at the same time they put together the show. Artists are very happy to do this. They love their work, and they understand what's important." For instance, in every episode of CTV's *Odd Job Jack*, an animated production from Smiley Guy Studios, there is an extra track narrated *by one of the characters*. (emphasis added)

Parlamo: Parlamo is a patented Smartphone application that will deliver simultaneous, synchronized foreign language audio and audio description tracks (in English or Spanish) at any movie theater or at home. It targets hundreds of millions of moviegoers worldwide who are not fluent in the local language and exclude movies from their leisure activities. It is designed to run on hundreds of millions of devices operating under iOS (iPhone, iPad and Touch), Android and Microsoft Phone platforms. The app downloads an encrypted language or audio description soundtrack to the device; the app is free with users paying a small fee per downloaded language soundtrack (audio description soundtracks are provided at no cost).

I mentioned earlier that in the United States there are over 20 million individuals who are either blind or have trouble seeing even with correction—that amounts to almost 8% of our population. Whether one speaks of public or commercial broadcasting, why would a broadcaster—or any institution—not wish to tap such a significant and underserved portion of the population. There is simply a lack of awareness of the need and a misunderstanding of the public benefit that could result from reaching out to this population, not to mention the financial benefit that might be gleaned from this untapped market.

Here in the United States the principal constituency for audio description has an unemployment rate of about 70%. I am certain that with more meaningful access to our culture and its resources, people become more informed, more engaged with society and more engaging individuals—thus, more employable. With a focus on people's *abilities*, we will come much closer to greater inclusion and total access. ■ ABILITY

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vdrdc.org
afb.org
American Blind Skiing Foundation: absf.org
American Blind Bowling Association: abba1951.org
justhungry.com/2006/02/restaurant_blin.html



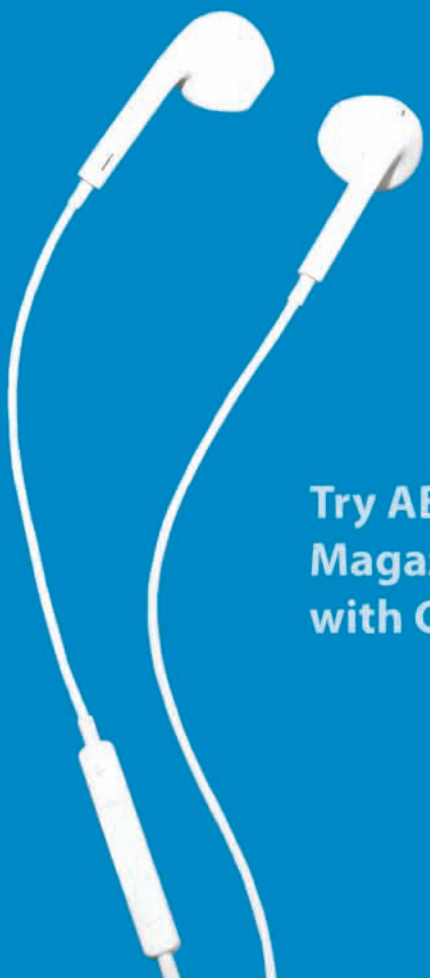
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Disability & DiverSitY

It's critical that employers understand the diversity and prevalence of disability, as well as what it means—practically and legally—in order to ensure an inclusive workplace for all.

For many, the word "disability" conjures images of individuals who use wheelchairs or who are blind or deaf. But according to a 2011 World Health Organization report, disability is a far more diverse part of the human experience; it affects all of us at some point of our lives, either directly or through a family member or close friend.

A functional definition of disability focuses on three areas:

Impairments with body function or alterations in body structure (e.g. paralysis, blindness); difficulties executing activities (e.g., walking, eating); and participation restrictions (e.g., lack of access to accessible transportation systems).

Disabilities can be visible or invisible, temporary or long term, chronic or episodic. Environment can act as a facilitator or barrier for individuals with disabilities. A person who uses a wheelchair, for example, may find their disability more salient in a multistory building without an elevator than in a building that is fully accessible.

While the above description is broader in scope, the Americans with Disabilities Act (ADA) and Amendments Act (ADAAA) offer more specific, legal guidelines that are critical to entities and employers in the US.

The ADAAA defines disability as "a physical or mental impairment that substantially limits one or more major life activities; a record of such an impairment; or being regarded as having such an impairment."

Key to this definition are such terms as "physical or mental impairment," meaning any physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more body systems (e.g., neurological, musculoskeletal, special sense organs, respiratory, cardiovascular, reproductive, digestive, genitourinary, immune, circulatory, hemic, lymphatic, skin and endocrine). Major life activities that fall in this category include, but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working.

A major life activity also includes the operation of a major bodily function, including but not limited to, functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions, according to the ADAAA. The law also provides examples of conditions likely to qualify as substantially limiting of a major life activity; this non-exhaustive list includes mental and physical, as well as visible and nonvisible conditions such as an intellectual disability, autism and cancer.

The ADA is often referred to as a "thinking person's law." Like all other civil rights legislation, it requires the application of independent judgment that can be highly specific to individual circumstances. For this reason, in particular, employers often seek guidance from Employee Assistance and Resource Network, the Job Accommodation Network and Regional ADA Centers in making ADA-related determinations in employment situations.

For example, although the ADA cites the reproductive system as a physiological function that could be covered under the ADA, if a disorder or other condition is not present, then pregnancy itself is not considered to be a disability. However, an employee who requires a leave from work on a regular basis to receive treatments for infertility might be considered to have a disability under the law, and entitled to request accommodation.

There are endless variations in individual circumstances that could require the application of sound judgment based on a solid understanding of Title I of the ADA, as well as other regulations that may have implications or interactions, such as the Family and Medical Leave Act. Some of the more common circumstances involve medical conditions that also rise to the level of disability, where intermittent or extended leave may be required as a reasonable accommodation.

Disabilities are as diverse as the individuals who have them. As you think about disability, I encourage you to move beyond the shorthand of wheelchairs, to think broadly about what constitutes disability both legally and functionally, and to translate that understanding to your workplace. ■ ABILITY

by Valerie Malzer

Valerie Malzer coordinates the development and maintenance of AskEARN.org and evaluates user experience on the site at Cornell University's Employer Assistance and Resource Network.

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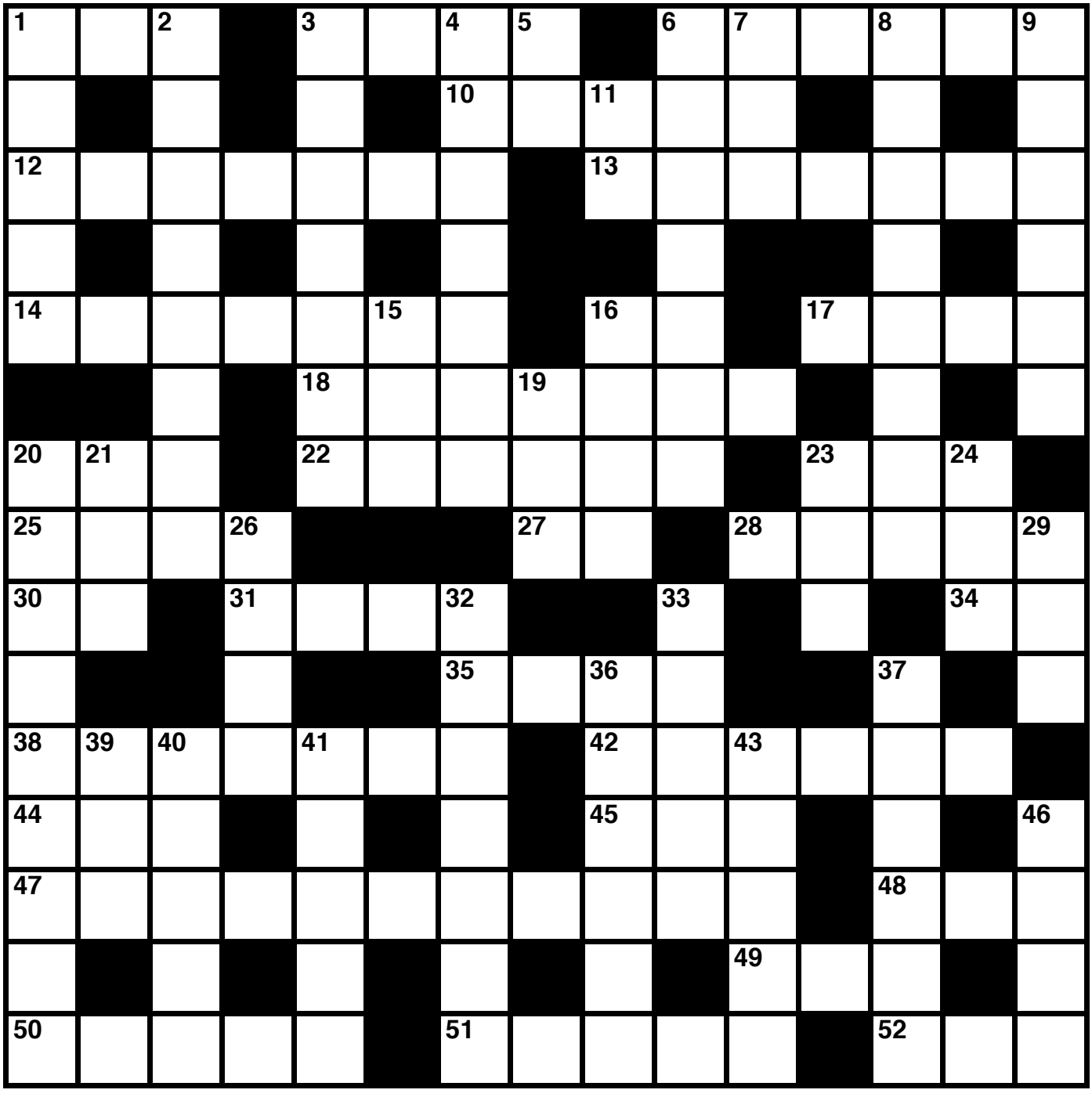
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Crossword Puzzle



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ACROSS

1. Robot created to teach kids with autism
3. Emotional boost
6. Co-introducer "Keeping all Children Safe Act" Sen. Chris ___
10. St Paul was one
12. "Sometimes all I need is the air that I ____ and to love you" Hollies
13. Guy who often has a pipe and a hat and a carrot nose
14. Enthusiastic
16. "Life of ___" film about a boy and a tiger
17. Beautiful Scottish island
18. Developing
20. Feminine, for short
22. "I Can Do This" singer who co-founded Children's Miracle Network Hospitals, Marie
23. Yoko from Tokyo
25. Coral collection
27. Compass point, abbr.
28. Fable wrote "The Bundle of Sticks" shows union gives strength
30. ___ Capitan
31. Speech problem
34. 50th state
35. Home for Samuel Beckett
38. "Charlie's Angels" actress who formed her own foundation, "Begin Today for Tomorrow" (first name)
42. "Little Women" author
44. TV network that produced a film called "I can't do this but I can do that"
45. Top executive
47. He played Ron Woodruff in "Dallas Buyers Club," Matthew
48. Kind of feeling
49. Escape
50. Indian breads
51. "Country Grammar" album rapper runs the 4Sho4Kids Found.
52. Shrek's companion is one

DOWN

1. With high ideals
2. "We Shall ____" one of the greatest songs of 20th Century
3. "Frozen" song by Idina Menzel (3 words)
4. What MLK fought for
5. Gift-tag word
6. All of us
7. One in Spanish
8. They have faces carved on them at Halloween
9. Derek Jeter, for one
11. Annette Funicello, the most famous Disney Mouseketeer, started a fund to research this disease
15. Hosp. trauma areas
16. Tree with cones
19. Triumphed
20. Inspector Clousseau, for one
21. Sushi fish
23. Over, old way
24. Little Richard's "___! My Soul"
26. Get out in a hurry
29. Word in a famous Edgar Allen Poe title
32. Bird that marched, as described by Morgan Freeman
33. More than a scuffle
36. First name of Daniel Craig's wife who supports the "Opportunity Network" charity helping students from low-income bak grounds
37. Shame, often created by having a condition that others dislike
39. Start of a learning song
40. Coffee order
41. "Dead Scared" actress who founded Born to Act Players, Mary ____
43. In a coquettish manner
46. He was sitting on the dock of the bay, in song

Crossword Puzzle

answers on page 64

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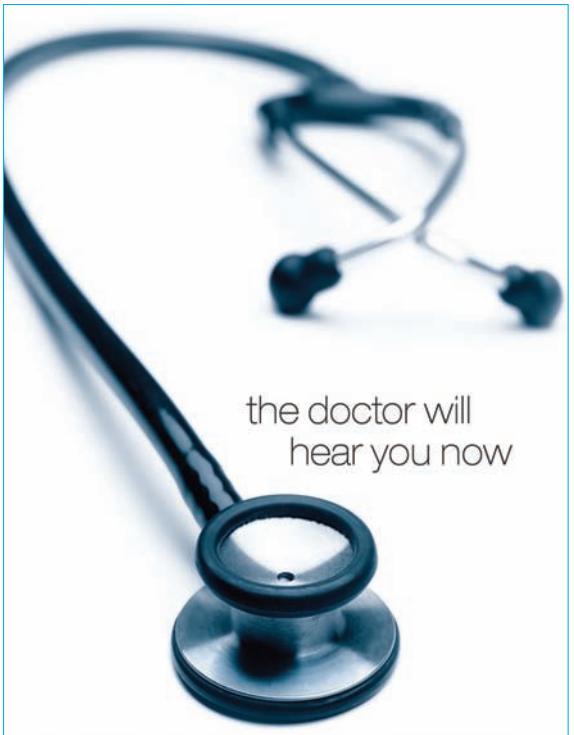
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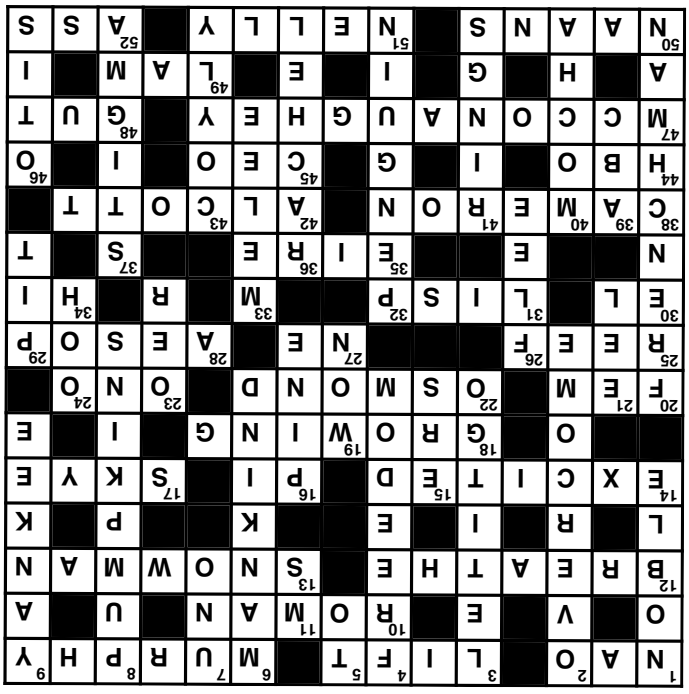
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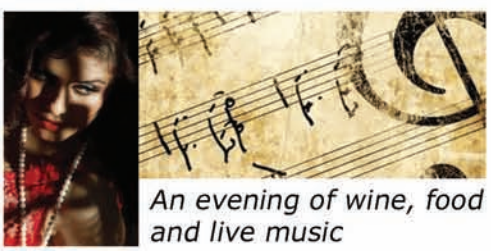












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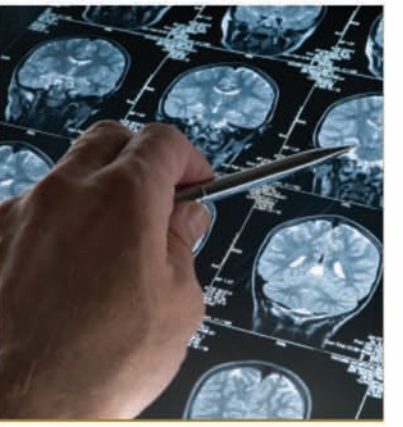
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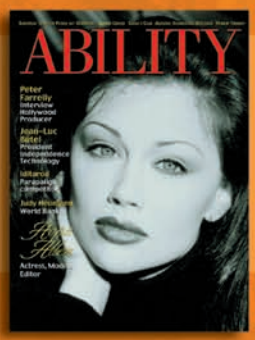


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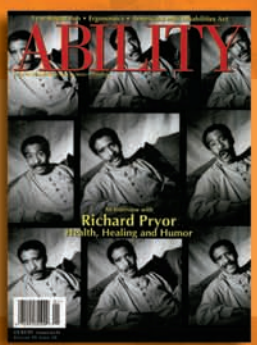
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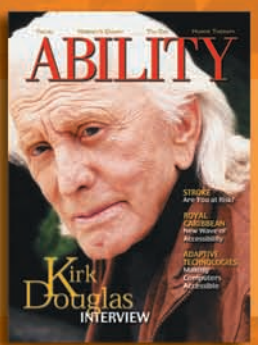
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