September 2018

New Horizons

Housing That Supports Independence

For Disabled Travelers, Technology Helps Smooth the Way. But Not All of It.

Reprinted from the June 25, 2018 NYTimes By Joshua Brockman

Technology is fast changing how people with disabilities get to and then navigate airports and train and bus stations. But technology can go only so far: Its advantages usually stop at the door of the plane, train or bus.

Consider the experience of Michael May, who is blind and typically flies at least once a week. Mr. May, the executive director of Envision's BVI Workforce Innovation Center, which provides employment training for the blind and visually impaired in Wichita, Kan., says he uses airline apps at home to secure his boarding pass, takes Uber to the airport and gets dropped off as close as possible to the Transportation Security Administration's PreCheck. (He's also enrolled in the Clear program to speed his way through airport security.)

But then he hits what he calls a void — he has to ask someone how to get to the security line. And in frenzied airports, he doesn't always get a response. "I'm looking forward to having indoor navigation to the point where I can at least get to PreCheck," he said.

Mr. May has a cane and Jonnie, his golden retriever guide dog. He also draws on screen-reader software and smartphone apps. He uses the free app **Be My Eyes**, which relies on a network of 1.2 million volunteers to provide directions through the airport via live video. In addition, he uses **Aira**, a monthly subscription app that uses a smartphone camera or a pair of glasses outfitted with a camera to live-stream video to an agent, who then provides navigational instructions. Ten airports, including ones in Seattle, Boston, Houston, Memphis and Minneapolis, currently offer zones where blind and visually impaired travelers can download the **Aira** app and use the service without charge. (Several more airports are expected to offer complimentary service this summer.)

David Wilson, the director of innovation at the Sea-Tac Airport, says blind travelers no longer have to rely on wheelchair attendants. "With **Aira**, they can get up and go to a restroom, go to a concession," he said. "It's independence."

Since 2014, Mr. Morris has taken more than 70 trips on Greyhound and Megabus combined. The lack of uniform setup for wheelchair boarding causes delays, he said. Still, the Americans With Disabilities Act, which became law in 1990, applies to airports and ground transportation — trains, buses and subways. But airline cabins are governed by the Air Carrier Access Act, which was enacted in 1986 and does not carry as many accessibility requirements. If, for example, someone uses a motorized wheelchair, it must be checked at the end of the jetway. Wheelchair assistants, often contractors, help the passenger transfer to a wheelchair that can fit down the narrow aisles and then to their seat (a foldable aisle wheelchair is also kept on board).

"The most accessible feature on an airplane is the fact that the arm rest lifts up to get in and out of the seat, and that's about it," said Lee Page, a quadriplegic who uses a wheelchair full time and serves as the senior advocacy director for Paralyzed Veterans of America.

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"My Two Cents"

By *Tim Doherty, Executive Director*

Every year, Marion and I and Tracee Battis, our Director of Housing Development, attend the Governor's Conference on Housing, which is always held in Atlantic City. Now I know what you are thinking, not much work goes on during that time, but probably lots of gambling. Not so, with me however. I learned a long time ago, that no one wins against the House. So, what I usually wind of doing is spending those dollars in the gift shop, rather than at the black jack table. At least that way, I bring home something for my son or daughter.

This year, I have been asked to be a part of a panel discussion on Supportive Housing. That means that I have to actually prepare a power point presentation about Project Freedom Housing and why we think our housing is a preferred design, when compared to other alternatives.

This is easy for me to do, since I live this job every day, and have a good idea as to what is successful and what is not. And the truth is it is really simple. Project Freedom housing's barrier free design, makes it easy for anyone to live in one of our communities. Whether you use a wheelchair or not, anyone can appreciate the functionality that our housing creates. Our units are larger than most, to accommodate a wheelchair; usually one story, or if two story, provide elevators in each building. They have lowered kitchen cabinets, ADA appliances, use sustainable outside materials and are Energy Efficient to the latest Energy Standards. Today, our new units are even LEED's certifiable.

But I think the most important part of this story, is that our units are built with the understanding that we are creating the most independent environment possible. Our homes are for those individuals who are capable of independence and in making their own life choices. They are not group homes, that are run by one agency, which have caretakers that oversee every ones actions. Now don't get me wrong, there is nothing wrong with the group home model, which does fit a certain target population. But our units are for that person, who although may be severely disabled, can make their own free choices, and can therefore live an independent lifestyle. All our tenants have leases, which give them certain rights and responsibilities for their apartment. They pay a rent, and for that, Project Freedom provides good housing, shovels the snow in the winter, and cuts the grass in the summer. We also fix anything that goes down in the units under normal course of business.

In the old days, prior to Project Freedom housing, the choices were very limited, to someone who uses a wheelchair. Either a nursing home or hospital were all that was available. Not a good choice for someone in their twenties.

Now however, things are different. Our housing model has spurred other developers to at least build more units that are accessible within their market rate housing. That housing, along with our barrier free housing model are helping to increase the choices for independence that all people what to enjoy.

From Norman's Desk

This month marks seventeen years since the attacks of September 11th. For many, the memory of that awful day is fading, but my memories are vivid down to my shirt and tie. The day started out so bright, beautiful, and refreshing and ended so dark and frightening. September is also National Preparedness Month when preparedness experts try to catch your attention to prepare for another, inevitable, dark and frightening day.

Every year since the attacks , I choose to honor three fragments that create my memory of that day. First, I honor the life of my friend and colleague Colleen Fraser who died on Flight 93 with those other selfless heroes who may have saved the Capitol or the White House or thousands of other lives. Colleen was a fighter, and she was in good company that morning fighting to take back that plane.

Second, I remember the lives of the 343 FDNY firefighters who died that day. Most knew going into those buildings that some of them would not come out alive. They knew this instinctively by virtue of their experience and profession. They still went in with police officers and EMS personnel to save those who could not save themselves. They went in to save people with disabilities.

And, yes, thirdly, I remember those people with disabilities who died that day in those towers. I was not watching the horror on television that morning. I had a meeting at 10 o'clock and during that meeting I spoke of Colleen and wanting to connect her with someone. Later, someone told me of the collapse. My very first thought was that many firefighters had just died; my immediate second thought was that many people with disabilities had died as well.

How many people with disabilities died that morning may never be known. We do know that the corporations and government agencies housed in those towers hired people with disabilities. We do know that some people with disabilities made it out because they had a plan, their company had a plan, or some colleague or friend took the initiative to get them out. We do know that others stayed behind not wanting to burden friends, not wanting to get in the way, or just having unwavering faith that the FDNY would get to them. We also know that loyal friends stayed behind with them. We know that some people with disabilities who stayed were rescued but many died with their rescuers.

Every victim of these attacks needs to be remembered and honored. I feel a personal duty to honor Colleen, The 343, and those almost nameless people with disabilities who stayed behind

Let us all remember the victims and the heroes of September 11, 2001, by getting prepared and staying prepared. You never know how a bright, beautiful, and refreshing day may end.

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A spokesman for Delta Air Lines, Anthony Black, said its gate agents must complete a “comprehensive accessibility curriculum” for travelers with disabilities that includes training on everything from handling service animals to transfer assistance onto a plane. A spokesman for United Airlines, Charles Hobart, said the carrier had a 24-hour accessibility desk and also trained all of the employees who work directly with customers on how to assist passengers with disabilities. Southwest Airlines said all of its customer representatives were trained to help customers with disabilities, and it maintained a video relay and a Teletypewriter number for deaf travelers.

But disabled travelers, including Teresa Blankmeyer Burke, an associate professor of philosophy at Gallaudet University, who is deaf, say airlines could improve their training. She said she would like airlines to do a better job of reassuring deaf and hard-of-hearing travelers that “our presence has been noted and that we will not be overlooked.”

Sheryl Stroup, a safety expert for the Association of Flight Attendants-CWA, said flight attendants were responsible for communicating directly with disabled passengers to make sure their needs are met. “You need to go ask them, ‘How can I best assist you?’” she said.

Ms. Blankmeyer Burke says she wears a brightly colored piece of clothing or a distinctive hat so that she’s readily identifiable and introduces herself to the ticketing crew at the airport, train station or bus terminal with a note. “I print out a script that tells the flight attendants a little bit about my communication needs and abilities, where I am sitting, and also notes my beverage preferences and my destination,” she said in an email. “In this document, I explicitly state that I want important announcements written and I ask who will be responsible for communicating with me in case of emergency.”

Bill McCann, the founder and president of Dancing Dots, a company in Phoenixville, Pa., that creates software to help blind and visually impaired musicians read, write and record music, said he navigated through the airport or an Amtrak station using the sighted-guide technique. He takes the arm of either the wheelchair attendant, a fixture at airports nationwide, or a member of Amtrak’s Red Cap team. At airports, he follows the attendant through T.S.A. PreCheck to his gate, keeping his cane out so people can identify him as a blind person.

“It’s a convenience,” he said. “It’s a timesaver. It reduces some of the stress of being in airports.” He said he viewed airports as “just below hospitals in terms of stress level.” At the gate, Mr. McCann said, he typically preboards — an option airlines must extend to anyone with a disability.

An accessibility consultant, John Morris, a triple amputee based in Orlando, Fla., uses a motorized wheelchair. He writes a wheelchair travel blog to share tips about air, bus and train travel. Since 2014, he said, he has taken more than 600 flights and over 70 trips combined on Greyhound or Megabus.

On Greyhound, an electronic lift carries the wheelchair user to a seating area that can accommodate two wheelchairs. But Mr. Morris said there was no uniform setup, and this caused delays. “Oftentimes,” he said, “I find myself being the one to educate the driver on how to operate the particular lift that’s set up on their bus.”

Delays can also make for an uncomfortable ride. When fellow passengers groan, Mr. Morris said, he feels like a “target sitting in the middle of the bus, and I have nowhere to go.”

Lawrence Events

DATE	DAY	PROGRAM (in Community Room)	TIME
4-Sep	Tue	Hamilton/Lawrence Shopping	Bus Leaves PFR 9:30 AM
5-Sept	Wed	Massage by Arlene	By Appointment
6-Sep	Thur	Lawrence Baking with Dana (Apple Sauce Brownies)	Prog. Time 5:00 -7:30 PM
10-Sept	Mon	Yoga	4:00 PM
12-Sept	Wed	Nutrition	7:00 PM
13-Sept	Thur	Keep Calm and Carry On	3-4:30 PM
19-Sept	Wed	Movie Day	2:30 PM
24-Sept	Mon	Yoga	4:00 PM
26-Sep	Wed	Lawrence Games	Prog. Time 3:00-5:00 PM

BMS Volunteers at Lawrence

Hamilton Happenings

DATE	DAY	PROGRAM (in Community Room)	TIME
4-Sep	Tue	Hamilton/Lawrence Shopping	Bus Leaves PFR 9:30 AM
13-Sep	Thu	Hamilton Baking with Dana	Prog. Time 5:00 -7:00 PM
25-Sep	Tue	Hamilton Games	Prog. Time 5:00 -7:00 PM

Robbinsville Events

DATE	DAY	PROGRAM (in Community Room)	TIME
5-Sep	Wed	Robbinsville Movies	Prog. Time 6:30 -9:00 PM
12-Sep	Wed	Robbinsville Baking with Dana	Prog. Time 6:30 -9:00 PM
27-Sep	Thu	Robbinsville Games	Prog. Time 6:30 -9:00 PM

Hopewell Events

DATE	DAY	PROGRAM (in Community Room)	TIME
5-Sept	Wed	Heart to Heart Chair Massage in Community Room	1:15 PM - 3:15 PM
7-Sept	Fri	Mercer Home Health Hosting Pokeno	3:00 PM
12-Sept	Wed	Hopewell Twp Animal Control Presentation on Local Wild Life and Safety.	3:30 PM
26-Sept	Wed	Heart to Hearts Chair Massage in Community Room	9:30 AM - 11:30 AM

Actually, I'm Not Fine

By Sunny Fitzgerald

Reprinted from The New York Times / June 18, 2018

My stepfather's voice came loud and clear over the whir of the wood splitter he was working 50 feet away.
"What in the hell is all that wailing?"

Only a moment before, I'd run into a rock with my bike and been tossed to the ground. I let out a shriek as I landed on the sharp gravel of the driveway. Splayed out on the stones now, I could hear the irritation in his voice. It was a Saturday; he had wood to stack for the long Northern New York winter ahead.

He flipped the switch on the wood splitter and it went quiet. I glanced up and saw him still standing by the wood pile with one fist on his hip, head tilted, impatiently awaiting my response. Warm blood flowed from the gash on my left knee. "I fell off my bike," I yelled back, trying to catch my breath between sobs.
"Jesus. You'd think someone died, screaming like that," he said, shaking his head. He flipped the splitter back on. "Get up. You're fine."

I wasn't fine. I was an 8-year-old girl, scared and bleeding on the ground. I should have gotten stitches that day; instead I got scolded.

My mother and stepfather are blue-collar, no-nonsense forces of nature — hardworking, blunt and unbending. Maybe they came into the world that way, or perhaps the punishing economy and harsh weather of our forgotten rural town had worn away their sense of empathy over the years.
I admire their strength, but I could never match it no matter how hard I tried.

My stepfather built our house with his own hands and often worked construction jobs even in the winter when temperatures could dip below freezing, and my mother juggled multiple factory jobs, standing on concrete floors for long hours in order to put food on the table and presents under the Christmas tree for our family of eight.

I knew they loved me. But I don't think they always liked me. While I inherited their strong work ethic, I'm a far cry from their type of tough. I am naturally empathetic, optimistic and sensitive. Even as a child, I was acutely attuned to other people's emotions. I was too sensitive, too curious and too concerned for the sort of people who prefer not to feel anything at all.

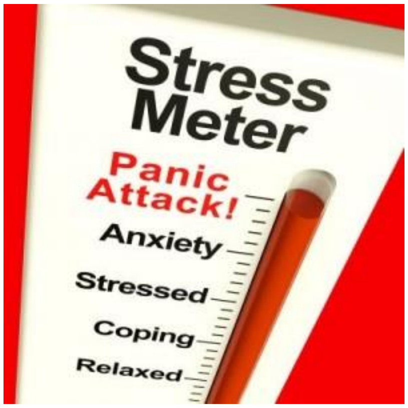
Dismissing pain was commonplace in our house, and weakness wasn't welcome. When my mother and stepfather said, "Oh, you poor baby," they weren't acknowledging my pain or expressing empathy. They meant: "Too bad. Toughen up." You can silence a child with those words, but you can't cure a neurological disease with them. I've tried.

As an adult, I discovered that I have sporadic hemiplegic migraines, a rare and chronic neurological condition with terrifying and sometimes paralyzing symptoms that mimic a stroke. It took me many years to acknowledge S.H.M. and seek proper medical care. When you're repeatedly taught your pain isn't real, sometimes you forget how to feel. And it's impossible to prevent or treat something if you don't even accept its existence.

I was in the car with a friend the first time debilitating S.H.M. symptoms surfaced. By that time, I'd become so accustomed to disregarding pain in any form, I insisted I was all right, even as visual auras blocked my sight and tingling numbness overwhelmed my face, lips, tongue and the left side of my body.
"Get up. You're fine," I told myself, as electric jolts pulsed through my brain.
"Too bad. Toughen up," I admonished, while orbs bobbed in front of my eyes.
I tried.

Despite the visual disturbances, pulsating headache and weakness, I carried on. My friend and I dropped by the department of motor vehicles to renew my license and cracked jokes about how I'd never forget this license photo — taken when I couldn't even see the camera through the pseudo-psychedelic dance in front of my face.

It was only when I picked up a magazine and couldn't grasp the meaning of the simple words written on the cover that I finally realized something was very wrong. My brain was cloaked in an impenetrable fog. I could not make out the shape of my own hands in front of me. I tried to form a short sentence, but couldn't recall a single word, or move my mouth to speak. No amount of "tough" was going to conquer this.



I ended up in the emergency room that day. After monitoring me and pumping me full of medicine to abort the S.H.M. attack, the doctor delivered a diagnosis and a warning. “You have hemiplegic migraines,” he told me. “You need to slow down.”
There it was, on official hospital letterhead: I wasn’t fine.

This time, there was no one to dismiss my pain. The doctor had given it a name. He didn’t tell me to suck it up. He’d advised me to slow down. Even my mother — the hardworking woman who taught me much of what I know about being tough — echoed his concerns. Her advice was no longer “Too bad. Toughen up.” Instead she begged me repeatedly to slow down, rest often, and take care.

I didn’t listen.
A lifetime of playing “I’m fine” couldn’t be undone in one doctor’s visit. It would take several more years, more attacks and more trips to the emergency room to convince me that this was not something I could tough my way out of.

S.H.M. requires an entirely antipodal approach. There is no cure and treatment options are debatable at best (some are arguably riskier than suffering through an attack). The only real hope I have is prevention and avoidance of triggers, which requires sufficient rest and low stress. Rather than “Get up, you’re fine,” it’s “Lie down, you’re exhausted.” Instead of “Toughen up,” it’s “Take a break.”

It was only recently — when S.H.M. came thundering in to disrupt an interview I was conducting near the Syrian border in Jordan — I realized how deep-seated and dangerous my need to appear just fine and tough enough really was. As I sat scribbling illegible quotations in my notebook while an attack overtook my eyes, face and the left side of my body, I thought, “This might be the last interview — the last thing — I’ll ever do.” S.H.M. is an electrical storm in the brain, and — given the agonizing power of the electric pulses I was experiencing that day — I couldn’t be sure whether this one would cause permanent damage or put the lights out completely.

I survived that attack, but while my body recovered in the foggy days that followed, I realized it was time to let go of this need to appear tough enough — or risk more serious physical consequences. Since that childhood day when I lay splayed on the stones in my driveway, I’d spent a lifetime believing that my pain wasn’t real, despite concrete evidence and a doctor’s diagnosis. Now, it was clear that acceptance of my pain was the only way I could ever hope to keep the symptoms of S.H.M. at bay.

When we teach people to deny their pain, we deny them the acceptance required to address what’s causing it. And that can have dangerous psychological and physical implications. You can’t treat something you don’t allow others, or yourself, to see.

As Americans, we live in a culture of “toughness” rather than one of empathy, one that values a stoic exterior no matter what sort of pain may be attacking the body or mind. And it’s not just about my medical condition; it’s practically universal. In trying to make sense in recent days of the apparent suicides of Kate Spade and Anthony Bourdain — two intrepid, wildly successful and outwardly high-spirited people — it seems a new segment of the public has also begun to think about the deadly costs of “toughing it out” and putting on the show we think others want to see.
We don’t need to toughen up. What we need now is to take care — of ourselves, our health and one another.

Sunny Fitzgerald writes about health, travel and culture. She is working on a piece of autobiographical fiction about trauma, love and memory.

Mr. Smith Goes To Hamilton

Project Freedom has always encouraged people with disabilities to vote and to learn where their elected officials stand on issues affecting people with disabilities.

n August, Congressman Chris Smith visited our Hamilton location to discuss various relevant topics of concern to our community.

September General Recreation

Club Freedom Events Highlighted

1-Sep	**Sat**	**Trenton Thunder Baseball Game**	**Bus Leaves PFR 5:00 PM**
3-Sep	**Mon**	**Labor Day - PF Offices Closed**	
3-Sep	Mon	Labor Day Picnic - Robbinsville	Prog. Time 11:30 -2:00 PM
4-Sept	Tue	Walmart Trip	Bus Leaves **8:30 AM—early today**
8-Sep	Sat	Aquatics Hamilton YMCA	Bus Leaves PFR 11:30 AM
10-Sep	Mon	Day Program - Robbinsville	Time Varies
11-Sep	Tue	Grocery Shopping - Shop Rite	Bus Leaves PFR 9:30 AM
11-Sep	Tue	Day of Remembrance & Service 9/11	
12-Sep	Wed	Equestrian Riding at Hopewell	Prog. Time Varies
15-Sep	**Sat**	**Lakewood Renaissance Faire**	**Bus Leaves PFR 9:30 AM**
17-Sep	Mon	Day Program - Robbinsville	Time Varies
18-Sep	**Tue**	**Dine Out - Dinner - Ruby Tuesday**	**Bus Leaves PFR 4:30 PM**
19-Sep	Wed	Equestrian Riding at Hopewell	Prog. Time Varies
21-Sep	**Fri**	**Amish Market Bristol 5 People Needed**	**Bus Leaves PFR 9:30 AM**
24-Sep	Mon	Day Program - Robbinsville	Time Varies
25-Sep	Tue	Grocery Shopping - Shop Rite	Bus Leaves PFR 9:30 AM
26-Sep	Wed	Equestrian Riding at Hopewell	Prog. Time Varies
27-Sep	**Thu**	**Columbus Farmers & Flea Market**	**Bus Leaves PFR 9:30 AM**

September 3
Danny DeMarco
Quinten Moultrie
Kevon Brown

September 10
Danielle Vitella
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Sept. 14
Jane Kovacs

September 18
Phyllis Ciampa

September 21
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Lakewood Renaissance Faire

$10 for Club Freedom Members only

Saturday Sept 15, 2018

Bus leaves Robbinsville 9 am sharp
($7 per person admission / $3 transportation)
NO REFUNDS
Bring extra money for lunch, etc.
First paid will have a seat on bus–
no reservation without payment!

Day Program attendees show off their kitchen utensil holders and “air plant” gardens that they made