Paralyzed Veterans of America Central Florida Chapter
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October Board Meeting is a Zoom/Hybrid - October 13th 10:30 AM

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Mission Statement
Paralyzed Veterans of America Central Florida, is a congressionally chartered veteran’s service organization that provides a platform of advocacy, education and research, communication, adaptive sports and recreation for veterans paralyzed as a result of spinal cord injury or dysfunction, in an effort to afford them with the highest quality of healthcare and life experiences.

Website: pvacf.org
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Kennedy Space Center is more than just a theme park. It holds an integral part of the United States’ advancement in space technology throughout history. It is one of the ten field centers of NASA and has been functioning as a primary launch center of human spaceflight. It also happens to be the only place in the United States where visitors can see rocket launches and space shuttle launches. Take a look at space travel equipment, rockets, and rocks from outer space, letting visitors know more about space travel and outer space.

The Rocket Garden of the Kennedy Space Center houses several NASA space-rockets and equipment. The Space Shuttle Atlantis Complex holds replicas of the rocket booster and external tank, and it gives you one of the best presentations about the historic missions in space.

*Come and Share in the Fun!*
Chapter President

Steve Kirk

With help I built my own bowling ramp, developed keyboard shortcuts for typing, and use “Alexa” extensively. I would be willing to share these hacks. I also have a monthly payment to amazon for supplies that the VA won’t supply. I’m not alone. Here is what Laura Mauldin has to report.

Today, tips and hacks are shared; they are actively discussed in Instagram posts, in online forums for caregivers, Facebook support groups, disability podcasts, and Twitter. For example, in late 2020, the disabled writer and activist Imani Barbarin tweeted the hashtag #AccessibilityAtHome and asked disabled people to chime in with their “most accessible household items.” Hundreds of people replied to praise Roombas, kitchen tongs, grabber tools, phone headsets, weighted blankets, pre-cut fruits and vegetables, and shatterproof glasses. The website Engineering at Home, created by design researcher Sara Hendren and anthropologist Caitrin Lynch, tells the story of, a woman who “survived a complex, life-threatening medical event.” She received “the best available ‘rehabilitation engineering’ technology that money can buy—a sophisticated myoelectric hand—and it turned out to be of little importance to her recovery.” What did matter was her “engineering with unlikely things.” The site describes devices she created by function: the category “pinch” includes hacks she devised such as adhesive wall hooks attached to the tops of containers to help her open them, and tongs and tweezers that can be used for grabbing.

On YouTube, the channel Zebreda Makes It Work is dedicated to specific disability life hacks for tackling functional tasks, while Natalie Fierce’s channel shares a glimpse of how different hacks and tips help her create a more accessible world at home. For example, Natalie, who has cerebral palsy, published a life hack video devoted to the Alexa Dot speaker. It tells her the news in the morning, plays the radio and audiobooks, and reminds her to take medication—and it does all this with voice activation. “I am dependent on people for so much, and this little thing has increased my independence a lot,” she says. And thus, we land on Amazon.

Over the last two years, I’ve spoken with dozens of spousal caregivers and some of their ill or disabled partners across the country about the hacks they use to navigate the world, and almost every person I spoke to talked about the key role Amazon plays in their lives. Though generally a malevolent force, Amazon is also a tool many disabled people have come to rely on to fill basic needs that our shambolic health care system often declines to recognize, let alone meaningfully address. In Pennsylvania, a couple were trying to problem-solve around Tina’s advanced multiple sclerosis. She only has the use of her right hand and forearm at this point. They got the idea to use an Amazon smart speaker from someone in his online support group. Now, she uses it to do most things on her own: Alexa keeps her grocery list, sends emails, adds appointments to her calendar, and even makes phone calls. They also purchased smart bulbs so she can tell Alexa to turn the lights on and off. She also uses voice activation on her iPhone, asking Siri to text her husband in the other room when she needs to get his attention.

But more than just being a way to increase the accessibility of homes by making as many things voice-activated as possible, Amazon has become a de facto medical supply company, providing access to materials quicker and more cheaply to doorsteps than almost anything else. In Wisconsin, Nancy was tasked with months of wound care following her husband’s leg amputation. The cost of bandages and gauze pads quickly added up, and their insurance coverage was inadequate. “They only pay for so much,” she said. After the initial specialized wound care nursing stopped coming, and all the care responsibilities fell to her, the insurance company effectively told Nancy that when it comes to the cost, “You’re on your own.” So she turned to Amazon to order in bulk “because they’re more expensive through the medical supply company.”

In Arizona, Sherry’s husband needed a hospital bed, but Medicare only covered manual ones—not electrical ones—and in order to adjust the bed, she would have to crank it by hand. Aging herself and solely responsible for her husband’s care, this wasn’t a feasible option. So she got the manual bed under Medicare and then bought an electrical, pressure-alternating mattress that fit into the frame so that her husband wouldn’t get bed sores. She found the mattress she needed on Amazon for a few hundred dollars.

It was a similar situation for Jake in Pennsylvania. His wife needed a wheelchair, as he had been reduced to perilously balancing her on the seat of a rollator in order to push her around. But the process and wait to get a chair customized to her needs and covered by Medicare was longer than they could bear. (This is due to Medicare’s reliance on competitive bidding, wherein companies fight back and forth to offer items at the lowest price—as well as the influx of private equity into the health care market. The result is long waits to obtain and repair wheelchairs and other durable medical
After a doctor’s appointment to get the prescription for the chair, the initial appointment with the wheelchair fitters turned out to be just an evaluation. Only months later were they able to schedule a second visit where a representative from the wheelchair company measured her. Then, they were told the wheelchair would take an additional six months to make. That’s when Amazon came into the picture: for a little over $100, they ordered a temporary wheelchair to serve as a stopgap measure. It arrived a day later.

Caregivers and disabled people are left to crowdsource improvised hacks to navigate a world indifferent—if not outright hostile—to their actual needs and desires. For Magnolia in Maryland, Medicare simply refused to cover the things her husband needed. “They’ll pay for a wheelchair, but then they won’t pay for another one for five years, and your needs might change, you might need a different kind of wheelchair by then,” she told me. “The kind of wheelchairs that they’ll pay for are very fancy, and that’s very nice, but he does not have the manual dexterity to use a joystick.” Her husband needed something called a transport chair—which Medicare wouldn’t cover because it hadn’t been formally deemed “medically necessary”—so they researched and got one off of Amazon. “I have very mixed feelings about Amazon as a company,” Magnolia said, “but man, oh, man, it’s so easy to browse through their stuff and find what you need.”

Others needed continuous positive airway pressure (CPAP) equipment, which requires a prescription. One woman in Texas told me how her Facebook support groups—which have thousands of members—taught her to find the supplies on Amazon instead. “If you can think of the question, you can ask it,” she said. “When you’re talking to that many people, you’ve got a wide availability of knowledge.”

People were often driven to Amazon because once they were discharged from rehab environments, they encountered obstacle after obstacle in their inaccessible homes. Bathrooms are particularly difficult to make accessible on a budget, and few Medicaid plans cover essential medical supplies like gloves, wipes, and bed pads—if one even qualifies for Medicaid to begin with. So they search Amazon for hours, to find a shower chair they can jury-rig as a commode if they pair it with a five-gallon paint bucket, or a shower chair that is mounted on a long bench with rails and then can be easily slid over and into a tall bathtub. These are things caregivers often find on their own and then share with their support groups, posting online to alert others that they’ve discovered something new.

That Amazon has stepped into the breach to fill a role all but relinquished by the health care system is indicative of a broader failure of social provisioning in the United States. While Amazon and insurance companies report billions of dollars in revenue, and innovators fantasize about the augmented reality glasses that will “fix” deafness, caregivers and disabled people are left to crowdsource improvised hacks to navigate a world indifferent—if not outright hostile—to their actual needs and desires. The failure to see disabled people as creative, collective forces worthy of our attention means that they’re left to make life work in a way that’s mostly invisible. Recognizing the creativity of disabled people, including those aging into it, can move us away from stigmatizing and toward valuing all the ingenious adaptations disabled people create.

Disabled people are everywhere. A recent report from the University of California, San Francisco, estimates that approximately twelve million people over the age of sixty-five living in their own homes need equipment to help them safely bathe and use the toilet, but about five million of them don’t have those items, even though they commonly cost less than $50. Meanwhile, the Centers for Disease Control and Prevention report about thirty-six million falls at home per year, resulting in tens of thousands of deaths—many of which could be prevented through the installation of grab bars and other simple home modifications. While some assistive equipment is astronomically expensive, price isn’t the only barrier disabled people encounter. As Dr. Kenneth Lam, a geriatrician and lead author of the study, told the New York Times, “You need whole systems to deliver it.” Even for people who want them, with the difficulties of selecting, ordering, and installing the devices, “it just doesn’t happen.”

The failure to see disabled people as creative, collective forces worthy of our attention means that they’re left to make life work in a way that’s mostly invisible. Disabled people’s hacks wouldn’t be so necessary if more attention were paid to the actual needs of disabled people in the design process—of homes, objects, infrastructure. It would, for instance, be relatively inexpensive to establish a national program to retrofit homes with simple modifications to make them more accessible, but the political will simply isn’t there, leaving the onus on the individual.

Our cultural obsession with technosolutionist thinking suppresses our ability to imagine alternatives to this individualist vision. It prevents us from dreaming up other more collaborative forms of creating and caring. But disabled people, and caregivers, too, are already building new worlds—rigging up different ways to do things and sharing them with their support groups. This is disability culture. Framing it as culture transforms the experiences of disabled people and caregivers from something thought of as isolated into shared knowledge and community. This is also crip technoscience. As Aimi Hamraie and Kelly Fritsch explain in their Crip Technoscience Manifesto, it’s about the “practices of non-compliant knowing-making: world-building and world-dismantling practices by and with disabled people.” Crip technoscience sees beauty in the daily innovations that disabled people create to make life work.
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Proud Supporters of the Paralyzed Veterans of America
I recently received a phone call from a friend, who is a local school board attorney, asking for my advice concerning an issue they were having at some of their schools. People were trying to take their dogs into school events claiming they were service animals when in fact they were not. This concerned me because many from our membership have service animals and a portion of the disabled community are very dependent upon their service animal. People, who use the ADA requirements concerning service animals to bring their pet dog to an event for selfish reasons, make it harder on those who genuinely need their service animal with them. Although I am certainly not an expert in this area and my friend was not seeking an expert opinion but rather advice from a friend, in order to give the best advice possible, I did a little research.

As most of us know, individuals with disabilities may use service animals and emotional support animals for a variety of reasons. Federal civil rights laws, under the American Disabilities Act, govern the rights of a person requiring a service animal. Many states also have laws that provide a different definition of service animal. If you have a service animal, it is important that you check your state’s law and follow the law that offers the most protection for service animals.

A Service Animal Defined by Title II and Title III of the ADA is any dog that is individually trained to do work or perform tasks for the benefit of an individual with a disability, including a physical, sensory, psychiatric, intellectual, or other mental disability. The work or tasks performed can include, among other things, pulling a wheelchair, retrieving dropped items, alerting a person to a sound, reminding a person to take medication, or pressing an elevator button. Emotional support animals, comfort animals, and therapy dogs are not service animals under Title II and Title III of the ADA. Other species of animals, whether wild or domestic, trained or untrained, are not considered service animals either. The work or tasks performed by a service animal must be directly related to the individual’s disability. It does not matter if a person has a note from a doctor that states that the person has a disability and needs to have the animal for emotional support. A doctor’s letter does not turn an animal into a service animal. Examples of animals that fit the ADA’s definition of “service animal” because they have been specifically trained to perform a task for the person with a disability are:

- Guide Dog or Seeing Eye Dog is a carefully trained dog that serves as a travel tool for persons who have severe mobility or visual impairments or are blind.

- Hearing or Signal Dog is a dog that has been trained to alert a person who has a significant hearing loss or is deaf when a sound occurs, such as a knock on the door.

- Psychiatric Service Dog is a dog that has been trained to perform tasks that assist individuals with disabilities to detect the onset of psychiatric episodes and lessen their effects. Tasks performed by psychiatric service animals may include reminding the handler to take medicine, providing safety checks or room searches, or turning on lights for persons with Post Traumatic Stress Disorder, interrupting self-mutilation by persons with dissociative identity disorders, and keeping disoriented individuals from danger.

- SSigDOG (sensory signal dogs or social signal dog) is a dog trained to assist a person with autism. The dog alerts the handler to distracting repetitive movements common among those with autism, allowing the person to stop the movement (e.g., hand flapping).

- Seizure Response Dog is a dog trained to assist a person with a seizure disorder. How the dog serves the person depends on the person’s needs. The dog may stand guard over the person during a seizure or the dog may go for help. A few dogs have learned to predict a seizure and warn the person in advance to sit down or move to a safe place.

Under Title II and III of the ADA, service animals are limited to dogs. However, entities must make reasonable modifications in policies to allow individuals with disabilities to use miniature horses if they have been individually trained to do work or perform tasks for individuals with disabilities.
While Emotional Support Animals or Comfort Animals are often used as part of a medical treatment plan as therapy animals, they are not considered service animals under the ADA. These support animals provide companionship, relieve loneliness, and sometimes help with depression, anxiety, and certain phobias, but do not have special training to perform tasks that assist people with disabilities. Even though some states have laws defining therapy animals, these animals are not limited to working with people with disabilities and therefore are not covered by federal laws protecting the use of service animals. Therapy animals provide people with therapeutic contact, usually in a clinical setting, to improve their physical, social, emotional, and/or cognitive functioning.

Without question, the general public has some responsibilities when it concerns service animals and adhering to the laws concerning them. However, the handler of service animals has some responsibilities as well. The handler is responsible for the care and supervision of his or her service animal. If a service animal behaves in an unacceptable way and the person with a disability does not control the animal, a business or other entity does not have to allow the animal onto its premises or to remain there once admitted. Uncontrolled barking, jumping on other people, threatening behavior or running away from the handler are examples of unacceptable behavior for a service animal. A business has the right to deny access to a dog that disrupts their business. For example, a service dog that barks repeatedly and disrupts another patron’s enjoyment of a movie could be asked to leave the theater. Businesses, public programs, and transportation providers may exclude a service animal when the animal’s behavior poses a direct threat to the health or safety of others. If a service animal is growling at other shoppers at a grocery store, the handler may be asked to remove the animal.

Here are some of the requirements of the handler under the ADA:

- The ADA requires the animal to be under the control of the handler. This can occur using a harness, leash, or other tether. However, in cases where either the handler is unable to hold a tether because of a disability or its use would interfere with the service animal’s safe, effective performance of work or tasks, the service animal must be under the handler’s control by some other means, such as voice control.

- The animal must be housebroken.

- The ADA does not require covered entities to provide for the care or supervision of a service animal, including cleaning up after the animal.

- The animal should be vaccinated in accordance with state and local laws.

- An entity may also assess the type, size, and weight of a miniature horse in determining whether or not the horse will be allowed access to the facility.

Titles II and III of the ADA makes it clear that service animals are allowed in public facilities and accommodations. A service animal must be allowed to accompany the handler to any place in the building or facility where members of the public, program participants, customers, or clients are allowed. Even if the business or public program has a “no pets” policy, it may not deny entry to a person with a service animal. Service animals are not pets. So, although a “no pets” policy is perfectly legal, it does not allow a business to exclude service animals.

When a person with a service animal enters a public facility or place of public accommodation, the person cannot be asked about the nature or extent of his disability. Only two questions may be asked:

1. Is the animal required because of a disability?
2. What work or task has the animal been trained to perform?

These questions should not be asked, however, if the animal’s service tasks are obvious. For example, the questions may not be asked if the dog is observed guiding an individual who is blind or has low vision, pulling a person’s wheelchair, or providing assistance with stability or balance to an individual with an observable mobility disability.

A public accommodation or facility is not allowed to ask for documentation or proof that the animal has been certified, trained, or licensed as a service animal. Local laws that prohibit specific breeds of dogs do not apply to service animals.

A place of public accommodation or public entity may not ask an individual with a disability to pay a surcharge, even if people accompanied by pets are required to pay fees. Entities cannot require anything of people with service animals that they do not require of individuals in general, with or without pets. If a public accommodation normally charges individuals for the damage they cause, an individual with a disability may be charged for damage caused by his or her service animal.

Keep yourself and your service animal safe and secure in all settings and please make sure that you are courteous and patient when attempting to enter a public facility. Not everyone knows the laws and how they apply. When you are in that type of situation, be an advocate and help educate without confrontation. Doing so, helps all those needing the assistance of a service animal.

John DeMauro
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September
What a fantastic Auto Museum.
It took us over four hours to see everything—cars from around the world. We saw cars from Cuba, France, Germany, Russia, Italy, Israel, London, and more. Cars from the era of the Great Gatsby, American Classics, cars from the Stars, Muscle cars, Duesenberg, and Military. I have never seemed so many Vespas, motorized bikes, and microcars. We took many photos and placed some of them on the website.

October
We plan to participate in Jeunesse Global Champions Ride for Charities on Saturday, October 22, 2022. This year it will be held at the Jeunesse Global 701 International Parkway, Lake Mary, Florida, 32746. Our Chapter is one of the sponsors, and we seek riders to participate. Hundreds of biking enthusiasts will be out riding. This is your opportunity to ride alongside fellow cyclists and support our Chapter and other worthy local charities in Seminole County. Choose your route to cycle 104 miles, 69 miles, 38 miles, and 8-miles. The ride begins and ends in Lake Mary, Florida. I’ll be cycling the 8 miles trail. I know my limit. The event is not a race, and all cyclists are welcome. There will be drinks and snacks to refresh and enjoy.

November
On November 11, 2022, we plan to visit Kennedy Space Center. Join us to explore outer space, where the future of space exploration launches occurs. My wife, Rosa, enjoys seeing the Space Shuttle Atlantis. Delve into the wonders of space, touch a piece of moon rock, take the Shuttle Launch Experience, and enjoy the feel of lifting off into space. We want all participants to be at the Victors Center at 10:00 am for group pictures. Once everyone has their tickets, you can visit the center alone or stay with the group. I recommend taking the tour bus and getting a comprehensive behind-the-scenes tour of the Kennedy Space Center. It is all spectacular. We hope to see you there.

December
The year has gone by so fast. It is hard to believe we are planning our Annual Christmas Party. We will give all of the particulars in next month’s events update. Stay tuned.
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GOD, Grant me the serenity to accept the things I can not change.
Courage to change the things I can and the WISDOM to know the difference.

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All a person is remembered for is what they did for others.

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