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# DisABILITYissues

*Providing people with disabilities, their families, friends, and advocates with relevant information that enables individuals to improve the quality of their life, health and employability options.*

**Vol 40 • No. 4 • Fall 2020**



## TABLE OF CONTENTS

**From the Editor...** | Marianne DiBlasi

**Ready & Able:** National Disability Employment Awareness Month -  
Make This One Count | Oswald 'Oz' Mondejar

**A President I Remember** | Mary Grimley-Mason

**The Opinion Corner I: The Desire to Be Free** | Penelope Ann Shaw

**The Opinion Corner II: Managing a Small Nursing Home in this  
Pandemic** | Anonymous

**Love and the Life of a Therapy Dog: An Autobiography** |

Sir Stubert Stevens, as told to Marsha Stevens

**Love & Intimacy Corner: Only the Sound of Silence** | Ms. Love

**Adaptive Yoga - Part 2** | Sandy Alissa Novack

### Information Briefs:

- Celebrate National Disability Employment Awareness Month
- Dignity Alliance Massachusetts - A Coalition of Disability and Senior Advocacy Organizations Form in Response to Nursing Home Deaths
- ADA Center COVID-19 Resources: New England ADA Center's COVID-19 Webpage
- Northwest ADA Center: Face Coverings and Businesses: Balancing the ADA with Public Health During COVID-19



## ***From the Editor...***

Dear Readers,

There is a lot going on in our world this October, much more than can be addressed in one issue of *Disability Issues*, so I and the dedicated members of our editorial board have selected a few relevant topics to share with you this month: National Disability Employment Awareness Month; the impact of a President; two perspectives on life in a nursing home; the joy and heartache of relationships; well-being of mind, body, and spirit; and the impact of COVID-19 woven throughout.

Even with this selected subset of topics, this issue is a bit longer than usual. I invite you to make a cup of tea and settle into a place where you can relax while reading through these articles, which were written for you – our dear readers.

For some people, reading poetry has the ability to invoke a sense of stillness and help them settle into the present moment. In that

spirit, I begin this issue by offering a seasonal poem for you to settle into.

## ***October***

*by Bernadette Williams*

Light in leaves in wind in sky.

Bright October brings beauty  
to dead things  
and the wingless learn  
to fly.

Berries try to stash the summer  
in their skin.  
Squirrels bury food  
and future forests.

Flowers fall back into all  
the abundance that birthed  
them and decay  
paves the way for life  
upon life.

When our dreams fall  
we might recall  
that forests are fed  
by the fallen.

What we call death is only  
the birth  
of bodies and dreams  
without boundaries.

What we call death is only  
the discovery  
that we belong  
to the beauty  
that burns in all beings.

With peace,  
Marianne DiBlasi, Editor



*Marianne DiBlasi has been the editor of "Disability Issues" since 2011. She was born with Spina Bifida and uses a combination of crutches and wheelchair to assist with mobility. Her background is in sales & marketing and disability inclusion training. In May 2020, she earned a Master of Divinity degree from Meadville-Lombard Theological School.*



## **National Disability Employment Awareness Month - Make This One Count**

***By Oswald 'Oz' Mondejar***

Certainly 2020 has challenged our community and the world in ways many of us have never seen. From the Global COVID-19 Pandemic to the growing chorus for racial justice, this year marks an important moment in time. For the community with disabilities, we find ourselves at a unique cross-section of all these issues. We are some of the highest risk groups for this dreaded disease and have felt the pain that institutional racism can bring.

Each year, October marks an important public campaign, **National Disability Employment Awareness Month** (NDEAM). However, for far too many organizations, this month only receives a polite cursory mention and the many events of this year are being used to say, "We



should wait until things settle down.” As an organization, all of us at Spaulding call on our fellow public and private employers to not pause at this critical inflection point but rather forge ahead.

Even before the pandemic the unemployment rate for persons with disabilities was more than double the rest of the population. As unemployment now climbs due to the pandemic’s impact, that will only exacerbate an already large divide. Businesses through necessity are reexamining how they operate, creating new models using remote technologies and more online services. They are being forced to adapt to the challenge before them. For the community with disabilities our hallmark is the constant ingenuity to find alternative ways to reach a goal. What better pool of talent to tap than those who are nimble, smart, productive...*ready & able!*

At Spaulding we have been finding alternative ways to run our organization, deliver care through methods such as telemedicine and using virtual technologies to bring the loving family to the bedside of a patient when they aren’t able to safely share the same space.



Change and uncertainty challenges us all. But that doesn’t mean we have to revert to old ways or maintain barriers both real and imagined for comfort or tradition. Use this October to chart a new course. To have the strategic foresight to see the growing movement to more remote technology and flexibility organizations should engage with people that have been practicing it their whole lives. Together we can narrow the employment gap, support our economy and most importantly empower our fellow community members. So next October as we all hopefully are in a better place together, your organization can look at your new approaches and know that not only

was it the right thing to do, it was simply good business.

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*Oswald 'Oz' Mondejar, Senior Vice  
President of Mission and Advocacy,  
Spaulding Rehabilitation Network.*



## ***A President I Remember***

***By Mary Grimley-Mason***



My interest this year in following the news coverage of the presidential

candidates has made me look at the chronology of Presidents in my lifetime. I was rather startled to find that I have lived through fourteen Presidents. Each one could be said to represent a different stage in my life, but only one stands out as having a personal impact: President Franklin D. Roosevelt (FDR).

My first awareness of the President was when I was six years old. I had contracted polio in 1932 when I was four. I sat next to Roosevelt at Thanksgiving dinner, which he annually attended at Warm Springs, Georgia, a polio center that became part of the National Foundation for Infantile Paralysis.

My personal memories of this important occasion in my life are few, but my mother and my aunt (the only Democrat in the family) kept a very complete scrapbook of pictures, newspaper articles, and letters of the event and my six months residence there.



My family sent me to Warm Springs for rehabilitation because it was the best place for polio treatment and recovery. Along with sixteen other children, I lived in a house run by a housemother, Miss Harding. I was the youngest patient at the Foundation and I didn't know

anything about the President so when we drew numbers from a hat and I was told that I had the lucky number that would seat me beside The President, I was afraid it was something unpleasant. I was relieved when Miss Harding said I only had to eat one meal with the President.

My actual memories of this event are few, but I do recall that the President seemed to have a huge head and a big smile full of teeth. He cut my turkey for me and asked if I was all right. I could only nod my head. During the evening we sang songs accompanied by a man who played the banjo and we took turns singing "Sweet Adeline." I became very tired and I remember being carried out by one of the attendants at the end of the evening. When I put my head on his shoulder, I fell asleep and the place card autographed by the President must have fallen from my hand.

From time to time over the years, I have looked through the scrapbook because the President became a referent point for me in living and pursuing life with post-polio. The President, unfortunately, often had to hide his disability, which he took great pains to do when he gave a public address. His son or an aide would accompany him, holding on to his arm so that he could walk with a cane. However, when Roosevelt was not in a public role, he was tireless in working with exercises to improve his strength and walking, even with his whole family present, including his children.

The civil rights movement of the 1960s was a long way off. The Rehabilitation Act, which did much to change the perception of disability, was not passed until 1992 and it has taken a long time for social attitudes toward the disabled to change.

I was a Junior in high school when President Franklin D. Roosevelt died on April 12, 1945. Roosevelt's death was a shock to everyone, though many also realized how ill he was. In his address to Congress after Yalta, he sat in a regular chair for the first time while speaking

publicly. He began with an apology to congress excusing his “unusual mode of presentation” and citing the necessity of accommodating “ten pounds of steel on his legs” (his braces) – a rare mention of his disability.

I was not aware of this unusual public scene at the time, but I remember watching the newsreels after his death, showing his return from Warm Springs where he had died and the solemn military procession that carried his coffin from Union station to the White House. We were told that at least 500,000 people watched silently as the casket went by and hundreds of mourners attended the funeral in the East Room of the White House, while thousands more gathered outside along the iron fence. After the ceremony, the coffin was placed on a train for burial at Hyde Park.

Several decades passed before I once again became personally connected to Roosevelt. In the meantime, I had lived through five presidents whose tenures had engaged me politically: Kennedy, Johnson, Carter, Nixon, and Reagan. I became involved in the civil rights movement in the sixties, the feminist movement in the seventies and eighties, and the disability movement in the nineties.

In my activism, I once again renewed my admiration and debt to Roosevelt. I realized that all the civil rights legislation I was fighting for would not have been possible if Roosevelt had not pushed through the Social Security Act of 1935, which for the first time acknowledged that the government could do more for U.S. citizens than protect them militarily.





Frances Perkins, standing behind President Franklin D. Roosevelt.

We now know that this great legislation was primarily accomplished by Roosevelt's Secretary of Labor, Frances Perkins, the first woman to serve in a Presidential cabinet. She is among the women I most admire. As Governor of New York, Roosevelt had worked with Perkins as his States' Industrial Commissioner when both were aware of rising unemployment and dangerous working conditions. Perkins agreed to go to Washington on the condition that FDR would accept certain policy principles. She outlined a program that included all the labor reforms we now take for granted, such as a forty-hour workweek, a minimum wage, and unemployment insurance. The only bill that was not passed was for universal health care.

In the 1980s, I went with a group of friends to visit Campobello Island in New Brunswick, Canada, where Roosevelt had summered since the age of one and where he was stricken with polio at the age of 39 in 1921. We enjoyed the pleasures of the island as well as the history and tribute to the President in films and displays, but I did not feel a personal connection until we toured the house and the bedrooms. Then I realized, this was the place where the President had

experienced his illness and the various inept diagnoses and treatments that the medical world tried when polio first became recognized. Eleven years later in 1932 when I became ill, the knowledge and treatments were still inept.



LEFT: Roosevelt's summer home in Campobello Island. RIGHT: President and First Lady Franklin and Eleanor on the beach with guests on Campobello Island

In the 1980s, I went with a group of friends to visit Campobello Island in New Brunswick, Canada, where Roosevelt had summered since the age of one and where he was stricken with polio at the age of 39 in 1921. We enjoyed the pleasures of the island as well as the history and tribute to the President in films and displays, but I did not feel a personal connection until we toured the house and the bedrooms. Then I realized, this was the place where the President had experienced his illness and the various inept diagnoses and treatments that the medical world tried when polio first became recognized. Eleven years later in 1932 when I became ill, the knowledge and treatments were still inept.



In the 1990s, I finally went to Hyde Park with my son and his family. We visited Roosevelt's grave and his family home, Springwood, where he grew up as a young man. Inside the Springfield home, I

enjoyed observing pictures and memorabilia. When reading about Roosevelt's early life, I discovered that he, my father, and I had all lost a father early in our lives. Roosevelt's father died in 1900 when Franklin was eighteen. It was said to have caused him great distress. My father was twelve when his father died and I was thirteen, only a year older when I lost my father. These connections gave me a special feeling about my visit to Hyde Park. It became part of my pilgrimage to honor the President but also to remember him as someone who had personally touched my life.

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*Mary Grimley-Mason is a PhD Professor of English emerita, Resident Scholar, Brandeis University's Women's Studies Research Center, and author of; "Life Prints: A Memoir of Healing and Discovery, Working Against Odds: Stories of Disabled Women's Work Lives", and "Taking Care: Lessons from Mothers with Disabilities."*



## The Opinion Corner

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### The Desire to Be Free

***By Penelope Ann Shaw***

I am a long-stay resident of 18 ½ years in a nursing home. Not by choice but because of public policy.

I am acutely aware of the deficiencies of institutional life and why you

would never want to live in a facility. In mine, I have received services from some truly terrific caring staff who worked to see that I received quality care and a good quality of life. But I have also experienced paternalism and lack of self-determination from management and staff, rather than friendly conversations. I have experienced a lack of privacy in shared bedrooms, a lack of dignity and respect, actual neglect, flawed delivery systems, lost clothes and mail, not receiving the food I ordered on meal trays, or no food tray at all, and a physician who had me on 8 unnecessary drugs, which I was able to get off of. Much of these conditions are due to chronic understaffing by an owner who puts profit over care. Another serious issue is, as a person with I disability, they have low expectations for my ability to engage in rehabilitation to improve my functioning. Only after many years, it was a physician in the community who suggested I get a power chair. It liberated me.

I am a permanent resident not because of my health status, but because I have a significant physical disability which requires high-level needs assistance, requiring access to 24-hour, 7 days a week care, which is more PCA hours than the current MassHealth (Medicaid) policy will pay for if I lived in the community. My personal financial resources are too limited to obtain care in an alternate setting. People like me are thus not fully funded for community-based integrated care. Those of us in the disability community have long worked to see that all individuals with disabilities have the right to live in communities of our choice and to receive needed services and supports there.

As a member of the Coronavirus Commission on Safety and Quality in Nursing Homes, I now know only too well how living in congregate sites has resulted in death by institutional bias for many people, often because of poor infection control practices. We mourn the tens of thousands of people with disabilities who have died in nursing homes, in psychiatric facilities, in intermediate care facilities. These are not numbers. They are mothers, fathers, sisters, brothers, friends, neighbors, co-workers - all human beings with dignity and worth.



I reflect on the Olmstead decision and 2020 being the 30th anniversary of the passage of the Americans with Disabilities Act. I underscore the urgency for those of us in the disability community to address the unfinished work of liberating those of us still living in institutions by organizing and contacting policymakers to defund nursing homes as we know them. We need to see to rebalancing long-term service delivery away from an institutional model toward home and community-based services.

We can liberate people from institutions by developing new models of cost-effective, community-based, integrated LTSS housing and care. I suggest the disability community find pilot funding to develop a disability-community-designed and disability-run community non-profit co-op housing model with centralized PCA service offices to maximize efficiency. We should also own and manage non-profit PCA service agencies to see that all people with disabilities can live in the community location of their choice. These innovations would facilitate individuals with high-care needs – who are all too often relegated to institutions – getting housing and care in an integrated way.

At age 77, I still dream of finding a way to make community living possible for myself and all persons with disabilities, being able to be free, living more comfortably with choice and control, and being able to age in place in a more humane way.



*Penelope Ann Shaw, Ph.D., has a complex physical disability from Guillain-Barre Syndrome. She is a state and national advocate who uses her personal experiences to push for public policies that will improve the lives of children and adults with all types of disabilities. In Spring 2020, she was appointed as a member of the*





## **Opinion Corner**

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### **Managing a Small Nursing Home in this Pandemic**

***By Anonymous***

Whew! So far we have dodged the bullet – no staff infections, no patient infected or dead, even though another upscale nursing home in our Boston suburb had lost 55 residents and staff to COVID-19 by June 1st . Dignity Alliance Massachusetts, a Coalition of Disability and Senior Advocacy Organizations, reported that “...in just over five months more than 5,600 people have died in 379 Massachusetts nursing homes, 88% of the 429 homes in the state, and the toll increases daily. These deaths comprise 15% of all nursing home residents in the state and nearly 66% of all Covid-19 deaths in the Commonwealth.”

In our little facility, we have endeavored to keep the coronavirus outside our doors by insisting that our staff, who are all part-timers with other jobs, practice wearing face masks that we and their union provide at all times (at work in all jobs as well as off duty), wash their hands frequently, wear gloves when working with a patient or with food, very importantly avoid social gatherings, bars, restaurants, and public events in their private lives. We are determined not to become

another sad statistic; we want our staff to stay safe so no resident has to suffer.

Other disturbing facts the Dignity Alliance reports: *"Over 24,000 nursing home residents and staff have tested positive [by July]. The mortality rate of infected nursing home residents is more than 22%, three times the rate of the general population."* By instituting strict precautions near the outset of the pandemic in March, our nursing home has so far not needed to report a single infection or COVID-related death. We know that Massachusetts and the nation are not out of the woods, with a fall resurgence of coronavirus anticipated. So, we will continue to persevere with ever-vigilant precautions.

We are aware that strict isolation from family and friends can take a toll on a resident's mental health, even affecting physical health. In fact, there have been indications that such isolation can contribute to a resident's early decline into dementia. This is why we encourage social media contact online and by phone, as well as social activities with staff in-house – movie nights, interactive games, shared meals, and other resident-initiated activities.

Also of value for resident wellbeing, we feel, are socially distanced outings to enjoy the sun on our spacious deck with its flowering hanging plants and wheelchair height garden beds, allowing for resident planting and tending vegetables. There is something therapeutic about watching plants sprout and grow, tending to them by watering, weeding, pruning, and then harvesting – not that our amply stocked kitchen's pantry actually required all those tomatoes, onions, zucchini, and eggplant.

We agree with Dignity Alliance that *"Everyone deserves to live a full life with dignity. However, Covid-19 has robbed many of that right."* As the manager, I endorse this principle wholeheartedly because, you see, this nursing home is a one-bed facility staffed by three PCAs, and I am the sole occupant. I realize how very fortunate I am to be able to

afford this modest solo nursing home, to fund its operation with my monthly Social Security checks, and to staff it through the MassHealth PCA Program.

Unlike Dr. Penelope Shaw, I *am* relatively free – free to direct my own care, free to decide what I eat, free to set the time I’m gotten up, free to choose my daily activities, free to choose what time I’m helped into the rickety antique iron and brass bed that I rescued from a junk store fifty years ago, not into a hospital bed in a shared room. But I must also take full responsibility for the management of this little nursing home, pay the bills, order supplies including PPE (personal protective equipment), recruit and direct the staff, make and enforce the rules that keep COVID-19 outside the front gate while constantly worrying about full adherence to the CDC guidelines in their other jobs and community activities like shopping, errands, and gassing up the wheelchair van

As I drift off to sleep tonight, I’ll dream Penelope Shaw’s dream *“of finding a way to make community living possible for myself and all persons with disabilities, being able to be free, living more comfortably with choice and control, and being able to age in place in a more humane way.”* That, for sure, is what I am trying to achieve for myself; I wish I could do it for her as well.



**and the**

# **Life of a Therapy Dog:** ***An Autobiography***

**By Sir Stubert Stevens**

**as told to Marsha Stevens**



**Hello**, my name is Sir Stubert Stevens. My friends call me "Stubie" for short. My pediatric veterinarian, who is British, thought that I should be knighted. I don't take it seriously though. I don't know who my parents are or what breed I am, but people say I'm handsome. Sometimes people play a game of guessing what breed I am. My mom calls me a Pure Bred Bitza. She laughs and says that means I'm "bits of this and bits of that."

I was born in Knoxville, Tennessee which is a long way away from here. A doctor in TN found my brother, Rufus, my sister, Darla, and me on his doorstep when we weren't even a day old. We were in a box that was taped shut. Thankfully, the doctor had experience with newborn puppies. He was able to give us the right formula and warm us up because it was snowy that morning and we were very cold. Interestingly, the cold may have saved our lives. The people loved us and took turns taking care of us day and night until we were old enough to find forever homes. I was very close to my siblings and I was very afraid of what life would be like without Darla and Rufus. I loved the people in Tennessee, but I knew I needed a family of my own.

Not too many people were interested in adopting puppies who had



such a rough start and were from so far down South. I was four months old when my mom, Marsha, saw my picture and read my story. At the time, she was very sad because Moo, her dog, had recently died. She loved Moo a lot and missed her, but mom said she still had room in her life and in her heart to love another puppy. The cat, Big Max, missed Moo too. Big Max told my mom to visit me and see if I wanted to come home to Hingham with her. I didn't know where Hingham was, but I liked Marsha and wanted to give it a try. It took a long time for me to adjust to being a Northerner. Everything was different, including how the food tasted and smelled. In Tennessee, I loved to chew on wood, but the wood in Hingham didn't taste the same. When I first arrived, I missed my friends and my Tennessee family, so I was very quiet. I wasn't sure I was going to love my new life, but mom loved me, and Big Max Cat thought I was okay too, so Hingham soon became home and I don't worry about the wood tasting differently anymore.



Young girl hugging Stubert.

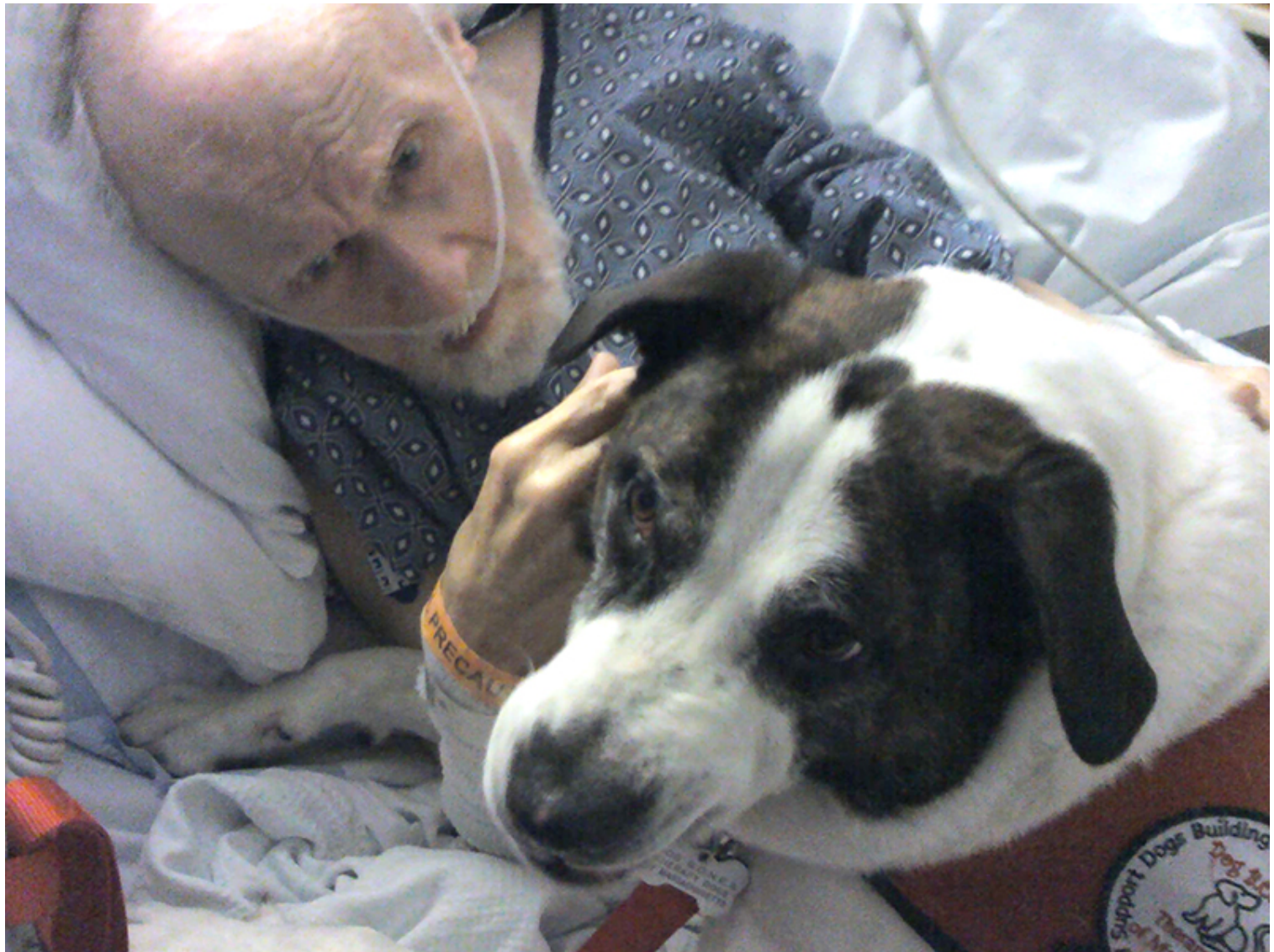


My mom has a lot of friends who have disabilities. She always introduced us, and I liked it when they talked to me and patted me. When someone was sad or nervous or thought they couldn't do something, like get a job, I walked over to them and they patted me. I liked that, so I snuggled up for more. I also discovered people often stopped crying or shaking, or even yelling when they patted me. Since I'm a really good listener, people practiced reading to me and I'm happy when they tell me they got an "A" in reading. It's also fun to see how excited people get when I listen to them and do what they ask. If someone is sad because they think no one cares about them, they feel better when I listen to them and give them kisses. Sometimes I give kisses for no reason, just because I want to! I was also pretty good at learning the manners my mom taught me. I have a lot of diplomas, including one from obedience school and another from the American Kennel Club. Mom puts them on the wall and gets excited when I get another one, so they must be good things.

Mom saw I was good at learning manners and making people feel better so she thought I might like being a therapy dog. I wasn't sure I wanted to go to school for as long as it takes to become a therapy dog, but mom thought I should try it since I was already quiet, friendly, and liked my people friends. A little while later, I began taking therapy dog classes through B.O.N.E.S. That was a lot of work! I had to pass a lot of tests and every time I did, they put a silly black hat on me and everyone clapped. Sometimes I took a bow and they clapped some more. Mom didn't teach me to bow. I saw another dog do it and it looked like a good way to get claps and a hug. Mom is proud of me.

I have a special love for my family. My family is my mom, Marsha, my Uncle Jon, and the cats Big Max, Squeaky, and Randy Panther. We like to snuggle. The cats sneak under me and eat my food. I think it's fine, but mom chases them away and says they should eat their own food. Sometimes I eat their food for dessert.

I had a special friend, Ted. He was part of my family too and we had a very special love. He was old and had a lot of disabilities. When he was in the hospital or at a rehab center, I was able to visit him because I'm a therapy dog. I got to snuggle with him in his bed or sit with him when he played the piano. Sometimes I sang when Ted played the piano and Uncle Jon played his harmonica. Ted would give me treats or smuggle some of his dinner to me when no one was looking.



Feeling the Love. Ted and Stubert.

I'm very sad right now because mom said Ted died and I won't see him anymore. A few days ago, mom brought some of Ted's things home. I could smell him in the clothes and looked all around the house but couldn't find him, so I know mom's right; I won't see him again. Ted loved me and I still love Ted. Sometimes I don't think I'll be able to love someone else, but then I remember the story mom told me about my adoption. She loved and missed Moo a lot after she died, but mom still had room in her heart and in her life to love a new

puppy. So, just like my mom, I can love and miss Ted a lot, and still have room in my heart and in my life to love a new person.



People can request visits with therapy dogs. The therapy dog group that we're members of is B.O.N.E.S. and they don't charge for visits. B.O.N.E.S. has therapy dog teams throughout Massachusetts and can make referrals to therapy dog groups in other places. For more information, call **Dog B.O.N.E.S. (781-264-5537)**

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**Sir Stubert Stevens, AKC-CGC, TD B.O.N.E.S.**, is a therapy dog with six years of experience. He is known for his caring and love of family, friends, and total strangers. He has provided his calming therapy to Boston College Law School, school groups, a church congregation struggling with grief and loss, and to numerous individuals, both young and old.

**Marsha Stevens, Ed.M., B.S.** is an Educational Consultant with a lot of experience in disability rights, advocacy, and a bunch of other stuff. Her most important role is that she is the soul-mother of Stubie.



Only the Sound of Silence

***By Ms. Love***

I am sensitive to noise, but lately I have been straining to hear the sounds I want to hear. No, it is not an issue so much with my ears, but rather with my heart. Let me explain.

My dear friend, Tuvye, died last week and this week I have been thinking about never again hearing the sounds I associate with him. For years and years, I knew Tuvye was approaching when I heard the tap-tap sound of his cane on the floor. I think the rubber on the bottom of his cane had worn down, so I heard the tap-tap of the cane itself hitting the sidewalk, stairs, and everything else as he walked. I also heard the sound of Tuvye frequently singing or vocalizing while he walked.

Then the day came when he needed to switch from using a cane to using a bare-bones walker. I missed hearing the tap-tap of his cane, the rhythmic sound I was so used to. Instead, I heard the sound of the walker trying to slide over a carpet or the two walker wheels that ran aground on an uneven sidewalk and stopped short with a bump sound. Eventually, he needed a wheelchair to accompany him on walks so he could use it when he got tired from walking with the walker. I heard the scuff, scuff of the walker as he pushed it in front of him, then quiet, as Tuvye paused to take a break. Then, came the whishing of the wheelchair over whatever ground we were crossing over.

In the long run, what difference did it make? I mean really, what difference? I still had my friend who made his way to the piano and masterfully played a wide array of difficult compositions and a friend whose voice could have sung with opera companies. And, I was still talking to him daily on the phone and seeing him regularly in person.

With the pandemic, Tuvye had to follow the policy of the facility he was in which required residents to stay in their room. No more trips down the hallway and certainly no more trips outdoors to feel the sun



on his face and to breathe some fresh air. I was no longer allowed into the facility to visit, so the only sounds I heard were his soft voice on the phone as we chatted and laughed and our mutual groans over current political, climate, and of course, coronavirus matters.

Months into the coronavirus, his soft voice became more and more infrequent as the isolation and loneliness of the pandemic weakened his body. Oh, how I wanted the phone to ring and hear his so soft voice say “Hi” and talk to me. But the phone stopped ringing as he was rarely able to project his voice enough to talk on the phone anymore. But I lived for the precious moments when I called him, and my ears were sometimes able to discern a bare whisper of his softest voice sighing with appreciation as I shared the day’s events, told stories and read articles to him, or thanking me at the end of our phone call for calling him. Other times, with much effort, he let me know he wasn't feeling well and tell me what was wrong.

When Tuvye was transferred from his long-term care facility to the hospital for the last time, he did not have the coronavirus, but he was seriously weakened by the isolation and loneliness caused by the long-term care facility coronavirus protocols. When my dear friend was dying, I was finally allowed into the hospital to see him. I was so, so happy to see him, but so, so sad to see the physical toll that not being able to have visitors at his long-term care facility had taken on him. When I first walked into his hospital room, my friend was sleeping and the only sounds I heard were the sounds of beeping on one of the devices he was hooked up to and the laughter and chatter of staff at a nearby nurse's station.

The days at the hospital are a blur of hospital sounds, but what I lived for was – any sound Tuvye made. Mostly, I did the talking with his medical providers but sometimes my friend would utter a few words to them as well. I lived to see his smile. When I read him a column I wrote for the summer 2020 issue of *Disability Issues*, a big smile lit up his face with approval, which lifted my spirits. But he spoke very few



words. At the end of that day, as I was getting ready to leave, he managed to push out a sentence, thanking me for coming to visit.

Soon after this visit, my beloved friend died. A few days after his funeral, the wind picked up and the sound of the tree branches blowing in the wind, the rustling of leaves attracted my attention. It was the most soothing sound I had heard since my friend died. But mostly what I hear is, instead of the tap-tap of my friend's cane, his singing, the daily phone calls, the scuff-scuff of the walker, the whishing of the wheelchair, the music he played on the piano, the hearty laugh and soft voice, the ringing of the phone and the voice messages he left me – instead of all the sounds of my friend – there is now only the sound of silence.

As I write this article, I hear a dog barking outside and a neighbor upstairs is dragging furniture, but I will never again hear the only sounds I want to hear. Oh, the sound of silence is so loud, so very loud. It is only broken by crying; the sound of my broken heart.



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*The Love and Intimacy Corner welcomes questions and requests for topic areas from readers. Please send all comments, questions and suggestions to Ms. Love at [DI.LoveandIntimacy@gmail.com](mailto:DI.LoveandIntimacy@gmail.com). Questions chosen to be featured in the Ms. Love column will appear under a pseudonym to protect privacy, and may be edited.*



# Adaptive Yoga

(Part 2 of 2)

***By Sandy Alissa Novack***

*Part 1 of this two-part article ran in the Winter 2020 issue before the pandemic came to Massachusetts. To accommodate articles about the COVID-19 pandemic and other timely topics, publishing Part 2 was delayed. If you missed Part 1 or want a refresher, visit the [Disability Issues archives](#) and view the Winter 2020 issue.*

**Gerson Silva** is a 40-year-old, multilingual Disability Peer Advocate at the Boston Center for Independent Living (BCIL). In the past, Gerson exercised at home by doing push-ups and stretching; at gyms, he swam and used machines. Gerson has post-polio syndrome and wears a Knee Ankle Foot Orthosis (KAFO) to support his lower left extremity and wondered what other types of exercise he could do. Then one day his employer, BCIL, began offering adaptive yoga for BCIL members and others with disabilities. Employees were also invited to attend; and the rest is history.

Gerson admits to initially feeling intimidated to try yoga, but after going regularly, he learned that while there are some traditional poses he may not be able to do, he can do them in an adapted way and get the same benefit. *"I do the same exercise, yet differently,"* says Gerson.

One of his medical providers told him it was important that he not overwork the muscles of the leg that is not wearing a brace, the so-called "good leg" because it is already compensating for the body part with the disability. Gerson finds yoga to be more adaptable to his circumstances without overworking his body. It also promotes proper posture and a state of relaxation, which helps him to rest.

Still, as Gerson grows older his balance is getting worse due to muscles continuing to get overworked in daily life. Therefore, his favorite yoga pose is what he calls the North-South Pole Position or Warrior II: He points his toes at 3:00 and 9:00 while pointing his

arms at 6:00 and 12:00 and bringing them up straight into the air. As he holds the position for 10 seconds, it develops greater balance. He practices the exercises he learned once a week, in addition to the class time. The more he does the yoga, the more he wants to.



Gerson Silva practices a yoga pose with the assistance of instructor Jeanette Olson.

**Michael Muehe** is a BCIL  
Access Analyst.

***"Before I started adaptive yoga,  
I had never been much of an  
exercise-oriented person. But, I***





*find that yoga is a good match for me because it offers good movement therapy while not being particularly strenuous. I like the focus on both mind and body, and on using meditation and mental imagery to complement physical movements. I use a power wheelchair that has a recline feature, so I can practice yoga poses that involve lying down, without having to get out of my wheelchair."*



**Austin O'Connor** is a bilingual clerical assistant at BCIL who has attended 20 adaptive yoga classes so far.

*"I keep going to the class because it gives me something to look forward to. It offers me an opportunity to unwind and meet new people. My favorite pose is the seated forward bend, also known as Paschimottasana. It entails placing the legs flat against the ground and reaching forward to grab your toes. This pose in particular helps to work my leg, arm, torso, and back muscles and gives them all a good*



***stretch. The class helps me relax and reduce stress."***

**Jeanette Olson** was a BCIL adaptive yoga teacher before the COVID-19 pandemic. She has been dealing with chronic pain throughout her life.

***"Though I saw many different doctors, tried a multitude of medications and worked with several holistic practitioners, it wasn't until I began working privately with another yoga teacher that I started to feel my body supported and beginning to heal. I focus on the ability to be fully present with myself and my students to observe the students' bodies and how they move. Ultimately, this feedback informs what use of movement and props (blankets, blocks, straps, sandbags, spinal strips, etc.) could work to support their bodies in a way that will help their pain. I have worked with people who have a range of disabilities including paralysis, spinal cord injury, neuropathy, MS, stroke, and more. Instead of working on moving the physical body, we focus our time on working solely with the breath and subtle body through the use of colorful imagery to describe what it could feel like if we were to move within the body, however, we are not actually moving."***

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I asked Jeannette some questions, which she generously answered:

**Q: If someone has never tried yoga before, or tried it but been unable to do it or like it, why should they give adaptive yoga a try?**

**A:** In general, I think it is important to try different types of classes and styles of yoga, as well as an array of different teachers. There are so many approaches to the practice of the umbrella term 'yoga,' and

sometimes it just takes finding the right teacher/class to make it all come together for you. Specific to adaptive yoga or all abilities yoga, sometimes the size of the class will be smaller, which allows the teacher the chance to spend more time with each student and adapt the posture based on the needs of the individual.

**Q: Any practical tips for someone who is just starting adaptive yoga? How soon should they start to notice a change and what kind of change would they notice?**

**A:** Have fun! Know that no matter how you show up to practice, you are enough. Show gratitude for yourself and for your body and all that it does for you. It is hard to say exactly what a student would feel after beginning to practice. For each person the experience is different from someone else; just like each of our experiences in life varies greatly. The wish for my students is that once they establish a form of regular practice, they will start to notice small changes in how they are feeling day-to-day. They could experience being able to breathe a little deeper after practice. Or possibly, pain in a certain part of the body is alleviated. For others, it could be the ability to slow down the mind and calm the thinking so that things don't feel so overwhelming. Whatever the intention is in showing up to practice yoga, it is important to remember that when we have completed our practice, we have done enough. Often we do not need to experience a big change; we are helping ourselves simply by being present with what we are feeling.

Due to COVID-19, BCIL began offering adaptive yoga classes virtually. For more information contact Shaya French, BCIL Community Organizer, at [sfrench@bostoncil.org](mailto:sfrench@bostoncil.org) or 617-338-6665.

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is a social worker, and a consumer advisor on the*



*Beth Israel Deaconess Medical Center's Universal Access Advisory Council.*



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## **Celebrate National Disability Employment Awareness Month**

In October, Americans observe [National Disability Employment Awareness Month](#) (NDEAM) to recognize the often overlooked talents that people with disabilities bring to the workforce and celebrate the importance of competitive, integrated employment.

This is a year of milestone anniversaries for the disability community as Americans celebrate 30 years of the Americans with Disabilities Act and 75 years of NDEAM. This year's NDEAM theme, *increasing Access and Opportunity*, reflects the impact of these two milestones.

NDEAM is led by the U.S. Department of Labor's Office of Disability Employment Policy (ODEP), but its true spirit of NDEAM lies in the many observances held at the grassroots level across the nation every year. The Campaign for Disability Employment (CDE) encourages organizations of all sizes and in all industries to participate in NDEAM. For ideas on supporting NDEAM, visit the website [www.dol.gov/ndeam](http://www.dol.gov/ndeam). Suggestions range from simple, such as putting up a poster, to comprehensive, such as implementing a disability education program.

However you choose to take part, you'll be playing an important role in fostering a more inclusive workforce, one where every person is recognized for his or her abilities—every day of every month.

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## **A Coalition of Disability and Senior Advocacy Organizations Form in Response to Nursing Home Deaths**

Everyone deserves to live a full life with dignity. However, Covid-19 has robbed many of that right – in just over five months more than 5,600 people have died in 379 Massachusetts nursing homes, 88% of the 429 homes in the state, and the toll increases daily. These deaths comprise 15% of all nursing home residents in the state and nearly 66% of all Covid-19 deaths in the Commonwealth. Over 24,000 nursing home residents and staff have tested positive. The mortality rate of infected nursing home residents is more than 22%, three times



the rate of the general population.

Dignity Alliance Massachusetts was formed to address the structural and systemic deficiencies which have created this public health crisis. They are committed to implementing and expanding access to essential care improvements and living alternatives that will make the Commonwealth a model of care and living choices.

Dignity Alliance Massachusetts, a grass-roots coalition of aging and disability service and advocacy organizations and supporters, is dedicated to secure fundamental changes in the provision of long-term services, support, and care. The coalition is pursuing an array of efforts to secure new public policies and to expand access to essential service and care options and living alternatives emphasizing the dignity of those receiving the care as well as those providing it.

For more information, visit [Dignity Alliance Massachusetts](https://dignityalliance.org).

Organizations and individuals interested in learning more about Dignity Alliance Massachusetts or becoming involved are invited to send an email to [info@DignityAllianceMA.org](mailto:info@DignityAllianceMA.org).

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## ADA Center COVID-19 Resources

New England  Center



A project of the  
Institute for Human Centered Design

**New England ADA Center's COVID-19 webpage**

People with disabilities have a right to participate in society even during a pandemic. The New England ADA Center has collected resources to help people understand their rights. Read more about how the ADA relates to programs and services provided during the COVID-19 pandemic. For more information, [click here](#).



## **Face Coverings and Businesses: Balancing the ADA with Public Health During COVID-19**

The **Northwest ADA Regional Center** has published a factsheet that covers what business owners may and may not ask customers with disabilities regarding their ability to wear a face covering. It further explains how to engage customers in interactive dialogue to identify a reasonable accommodation, examples of accommodations, and when an accommodation may not be possible. The factsheet also discusses whether a person has an absolute right to enter a business without a mask and the use of fraudulent exemption cards.

To read more, click [Face Coverings and Businesses](#).

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**Spaulding Rehabilitation Network** is pleased to be an underwriter of *Disability Issues*, a free and independent newsletter. The Spaulding Rehabilitation Network is a member of Partners HealthCare and includes Spaulding Rehabilitation Hospital. Spaulding Rehabilitation Network, a member of Partners HealthCare, includes Spaulding Rehabilitation Hospital, its main campus in Charlestown, which is a national model for environmental and inclusive design as well as Spaulding Rehabilitation Hospital Cape Cod, Spaulding Hospital Cambridge and two skilled nursing facilities, as well as twenty-five outpatient sites throughout Eastern Massachusetts.

Spaulding has been awarded a Model Systems designation in three specialty areas - Brain Injury, Burn Injury Rehabilitation, and Spinal Cord Injury - by the National Institute on Disability, Independent Living, and Rehabilitation Research. Spaulding is a teaching hospital of Harvard Medical School as well as the official rehabilitation hospital of the New England Revolution. Spaulding is the only rehabilitation hospital in New England continually ranked since 1995 by U.S. News and World Report in its Best Hospitals survey with a #2 ranking in 2018-2019. Spaulding was recognized in 2018 by Disability Equality Index® as a company who scored 100% in the category of Best Places to Work™ for Disability Inclusion. For more information, please visit [www.spauldingrehab.org](http://www.spauldingrehab.org)

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