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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.

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From the Editor....

Dear Readers,

Just like every news and media outlet are sharing stories and information about the COVID-19 pandemic, so too is *Disability Issues* bringing you a coronavirus-focused newsletter. When members of the *Disability Issues* editorial board met in April to discuss articles for the Spring issue, we spent a long time checking in with each other. We shared how the pandemic was impacting us personally and the wide range of feelings we were experiencing. It soon became clear; these were the stories that were important to share with our readers because sharing our strengths, vulnerabilities and responses to challenges can help us feel less alone in this difficult and uncertain time. Blessedly, currently, no members of the editorial board have contracted COVID-19, but the impact of the pandemic has been significant, as you will read about in this issues' articles. As the editor, I am incredibly grateful to the members of the editorial board for their willingness to write so honestly about their real-life personal experiences, while still being in the middle of living through the pandemic. With great respect and admiration, I am especially honored to bring you this issue.

I will take this opportunity to share a pandemic-related reflection based on my own experiences during this time. I am aware that people who live in non-disabled bodies are having a small taste of what it feels like to live with disabilities. One aspect that I've been particularly aware of is: At the congregation where I serve as the intern minister, before the pandemic I was primarily the one responsible for figuring out how to do ministry and lead worship services creatively and adaptively.

A few weeks after the pandemic began, I noticed the staff's fatigue and frustration that resulted from the huge amount of physical, mental and emotional energy required to continually be creative and adaptive – the daily lived experience of people

with disabilities. Quite honestly, I felt validated. Now everyone was having the felt sense of what it is like to live with a disability, to some small degree.

As time went on, I became aware of something else emerging at my congregation – the collective power of working collaboratively to re-imagine how to do ministry and lead worship services online. As creative adaptability became a shared responsibility instead of an individual responsibility, I was in awe at the number of changes that happened in a very short amount of time. As new ways of doing things began to take shape, I noticed a collective shift from fatigue and frustration to energized excitement at imagining even more creative possibilities.

I'm also seeing this shift happen nationally. The shared coronavirus pandemic experience is leading to a groundswell of collective energy and creative responses. Some of that creativity is expressed as art or home projects, as seen in a multitude of YouTube videos. The pandemic is also acting as a catalyst for people to come together to address systemic issues and inequities in healthcare, employment, food insecurity, housing etc. that existed before the pandemic but were less visible. People are working together to develop innovative solutions to address these challenges. There's nothing we can do to change the past, but the future is unwritten. We have the opportunity to bring something entirely new into the world and what we do right now will help create that future. It will require all of us to contribute our unique visions, passions, perspectives, and talents to co-create something greater than any one of us can create on our own.

I believe this is our time; a time for people with disabilities to tap into the groundswell of collective, innovative energy that is rising right now. A time for us to use our finely-honed skills of creative adaptability to participate in conversations and contribute our vast wisdom toward designing a future world that is more equitable and inclusive for all people.

Be safe, be well, and take good care of yourself and each other.

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.



Meeting up with the Coronavirus Pandemic

By Raymond E. Glazier

It was early March. As a 78-year-old quadriplegic, I had been feeling especially vulnerable listening to TV news of the pandemic night after night. “Thank God I’m not in a nursing home” I thought, reading in my community’s weekly paper of 35 COVID-19 deaths in a pricey local care facility. I have always felt fortunate to be able to maintain myself in my own modest home, shabby as it is, with the help of caring friends and long-term PCAs. But things in my peaceful private world were about to change dramatically, as by now they have for all of us in ways large and small.

On March 6th, M., a live-in caregiver of 12 years, thoughtlessly and seriously injured my right arm. You need to understand that my right arm is the only limb over which I have any control – how I feed myself, control my power wheelchair, use my laptop, write stories for *Disability Issues* – you get the picture. This fellow had never really wanted to be a caregiver, just needed a crash pad for all those years. On the morning in question he had been up most of the night playing online poker; he was sleep deprived and annoyed at having been called downstairs to get me up. M. yanked mightily on my arm, pulling it back over my head, trying to move all my 185 lbs. using my right arm as a lever. He had not meant to hurt me, but that did not lessen the pain. No bones were broken, but I sensed something had been torn.

At a routine doctor visit a few days later the widespread angry red bruising was alarmingly apparent upon my physical exam. The doctor quizzed me about how it happened, he snapped pictures with his cell phone and saved them to my electronic medical record. He called in the office social worker, showed her my arm, and recounted the story. She left the room abruptly, returning a few minutes later to say she had filed a suspected abuse report with Elder

Protective Services. A few days later the same guy carelessly reinjured the same arm, using it as leverage to help me out of bed.

The first time I had felt conflicted, not wanting to get M. in trouble. This time I had few such qualms. When the social worker called for a check-in, I told her what had just happened. She filed another abuse report. The next morning, before anyone in the household was up, an Elder Services caseworker was banging on the front door. Once inside, she came to the first-floor den where I sleep, ripped back the covers, snapped pictures of my arm, and called the police and an ambulance. She asked who held my healthcare proxy and phoned him too.

Soon the group gathered in my living room included: the caseworker, three sleepy live-in caregivers, two cops, a three-person ambulance crew, and my friend who holds both healthcare proxy and power of attorney. I was told I was to be transported to a Boston hospital for further evaluation. I protested, thinking of what I had read about COVID-19 in hospitals and fearing I'd be shuttled off to a nursing home in the end. Nonetheless, the ambulance crew slid me onto a stretcher, rolled me down my wheelchair ramp, and headed for Boston.



Arriving at the hospital, we found that the regular ambulance entry was reserved for respiratory cases, that is, patients suspected of having coronavirus. So I was taken through the main entrance and carted through the lobby to the ER circuitously. I lay on a gurney for hours before a harried doctor pulled back the curtain and entered, meticulously scrubbing his hands before bending down to examine me. "Don't you have gloves?" I asked. He mumbled something, took photos of my much-photographed right arm, ordered an x-ray, and left, leaving the curtain open. Now I could see that across the hall workers were hastily erecting more virus containment units. I had come face to face with

the pandemic. The x-ray, as I had suspected, showed no broken bones, and I was discharged hours later.

When I returned home, M. was loading belongings into his car, preparing to move out. The next day the real challenge began – trying to recruit a PCA to replace M. on the part-time staff of my one-bed nursing facility. In this issue’s PCA Corner I discuss the difficulties of PCA recruitment and hiring in this pandemic scenario, based on my as yet unsuccessful experience trying to do just that. If you or some you know is a potential candidate, please email Ray at raymondglazier@gmail.com for position details. Thanks.



Raymond E. Glazier, Ph.D., has decades of personal and professional experience with PCA issues both as consumer and researcher. He is the founder and principal of disAbility Research Associates, Belmont, MA. Please email questions or suggestions for future columns to raymondglazier@gmail.com



Locked In and the “New Normal”

By Mary Grimley-Mason

The process began on March 4 and continues. Every morning the director of our retirement community announces a new restriction necessary to keep us safe from attacks of the coronavirus, which is particularly dangerous for the elderly.

We are locked in completely now. Dinner is placed outside the door in a large paper bag, our mail delivered to a box outside the door, no visitors or staff (except for medical reasons), no going outside to walk or to leave the campus (again, except for a medical necessity).

There have been times when I really consider not listening to the announcements! But there is a written report delivered as well. No escape! It is hard: relentless, inevitable and suspenseful as I hear statistics and reports on all the media and my email. I try to adjust to the loss of real personal contacts though I see family and friends on Zoom and other social media.

And yet I am privileged with the kind of compassionate care I am getting from the directors and the staff who work around the clock to meet new developments. As a person with a disability, I am given some extra help with tasks I cannot do. I am glad that we are given the actual facts relevant to our community. The nursing home section of the facility has been impacted with about ten cases of the virus. These individuals have been moved to a different area with special care. Any staff that tests positive for the virus is quarantined. Testing has been provided by state agencies, even the National Guard. Despite my isolation, I feel part of a larger community – the state and even the country.

Is this the “New Normal?” This a major question that is being asked about the lifestyle that everyone (most everyone) is living during this pandemic.

Is this relevant for a person with a disability?

Ashley Shew, a multiply disabled professor at Virginia Tech has studied the intersection between technology and disability. She points out that the accommodations made for “the new normal” have long been developed and fought for by the disability community to help live their lives. She defines the new normal as “spatial confinement, unpredictable futures and social distance.”

She explains, “We know how to do community from afar, and how to organize from bed ... Everything I enter in my calendar has an asterisk in my mind...Instead of feeling this vacuum, our social life hasn’t really changed.”

This description is closer to my life as an elderly person living in a retirement community than as a post-polio survivor who has used crutches and braces most of my life. For many years I did not feel spatial confinement: steps were fine, even hills, though climbing mountains was not. Unpredictable futures and social distance don’t describe a thirty-year career of teaching. But, of course, no one can avoid unexpected future changes.

I think the problem for me is the phrase “the disability community.” What does that mean? The community is made up of many individuals. The disability movement and disability studies, fighting ableism and stereotyping, speak of “claiming” one’s disability as one would own any marker of diversity, such as gender, race, class, ethnicity or sexual orientation and acknowledging it as part of one’s identity but not as part of any generalization. Those activists and scholars who have fought ableism and stereotyping wish to see every disabled person as a distinct individual.

So, we have to ask each disabled person: Is the new normal your “old normal” The answers would vary, and each would be a different story, an interesting story.

My experience of this pandemic has made me realize that the description of the “new normal” - confinement, unpredictability, social separation - does apply to many groups of individuals. It is the story of many in our prison system, particularly those in solitary confinement; or the experience of hundreds of refugees torn from their countries and homes in refugee camps where often whole families live in one tent. It is also those confined physically and socially by poverty. The list goes on. Each category represents a group of individuals; each individual has a unique story to tell.

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.”



Physical Distancing vs. Social Distancing

By Ms. Love

I was appalled to hear we must socially distance ourselves during this pandemic. After all, your Ms. Love's very being calls out for all of us to be connected closely to each other. But it turns out that when the term “social distance” was coined, the intent was only for people to keep physically distant from each other in an attempt to “flatten the curve.” (My, look at how our vocabularies are growing with this pandemic!)

What does one do if one cannot be physically close to someone dear to you? Certainly, on the television news we have seen family members standing outside hospital windows waving to loved ones inside or singing to loved ones outside their houses. Recently, I even saw a photo of a crane lifting family members up to a loved one's Dutch nursing home window on an upper floor of the facility.



Relatives of Fiet Aussen get ready to meet her from a crane outside the window of her Jewish nursing home in Amsterdam, April 15, 2020

(photo credit: COURTESY OF RIWAL HOLDING GROUP/JTA)

Such examples are food for thought for me, but not quite right for my friend's situation. My friend is legally blind and would not see any banner I made to wave outside his window. His facility sure hasn't offered to hire a crane to lift me up to the level of his window so I can put my hand against one side of the window and my friend put his hand on the other side, allowing us to hold hands the best we can.

Which brings us to technology. Many a day, it has been hard for my friend to project his voice, which prevents me from hearing his words on the phone. His facility has offered Skype during the pandemic to other residents who can go down to the function room, but they have not offered it to my friend who is currently confined to his room due to a non-coronavirus illness. There is nothing so fraught with sadness as people trying so hard to connect yet being unable to do so. It is said, the other pandemic these days is isolation and loneliness. But I don't want either one of us to feel isolated or lonely because the pandemic is keeping us apart. I knew I had to try to be creative on the matter.

There are just so many times during each call that I can ask my friend to repeat his words so I can try to make out what he wants to say to me. He was

frustrated; I was frustrated. Rather than allow our frustration to build, after making a few attempts to ask him what he was saying on our calls, I switched to what was working well – he said he could hear me! We experimented with different ways of communicating. My first attempt was to see if he could hold his phone in one hand and tap it with his other hand, so if I asked yes or no questions he could tap once for yes and twice for no. Were you able to sleep last night? Am I calling you at a good time? Are you in pain right now? Unfortunately, my friend could not coordinate his tapping without disconnecting our call.

I threw out the idea of a 50-50 conversation. It became a 99-1 conversation. As soon as I heard the phone picked up, I listened for his soft voice. If it was a good day, I could hear him project enough to mouth a few words and I would carry the rest of the conversation myself. When the phone was picked up and there was no sound at the other end of the line, I would check my phone's Caller ID to make sure I had dialed the right number before having a half hour or longer monologue with a stranger. Once I was assured I had dialed correctly, I talked a blue streak telling my friend all the news of the day. This was everything from:

- Telling him the weather person said it will be cold tonight so you might want to put a sweater on.
- Describing everything and everyone I could see outside my window – trash being collected, people riding by on bicycles, a lot of dog walkers.
- How I put too little garlic in the soup I made and how next time I think I am going to put other spices in.
- How much laundry I just did.
- How I trimmed my own bangs. “Oh, so this is what the world looks like!”
- Who said what in politics today.
- Mentioning a bluebird just landed on my balcony and is looking at me while I talk to you. I wonder what he is going to say later in the day to his fellow bluebird friends. Maybe, that he saw me?

After a number of days of me carrying on the mostly one-sided conversation, I then thought of reading to my friend. I selected newspapers and magazines of his religious and cultural background. He seemed to especially enjoy articles about the geographic region where he grew up. I read recipes that seemed interesting. I researched and read long articles on artists, writers, and more.



You can be physically distant but close at heart.

If it was a good day for him, I often heard a sound of pleasure while I read something to him or at the end of what was sometimes an hour of reading. At the end of our call, I would say good-bye and he would thank me for calling. Sometimes I had no voice left myself after talking so long, but I hung up with a good feeling that we had shared space together. Although we live in cities far away from each other, we had created a space for us, our own space for connection and friendship.

Dearest readers, don't be fooled by those who say we need to practice social distancing during this pandemic. Yes, be safe and physically distance yourself from people outside your household to protect yourself and others. But socially distance yourself? Never! You can be physically distant but close at heart. And that, my friends, is what your Ms. Love wants for you, to be close at heart to others. Be safe, be well, and be close at heart.

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 Questions chosen to be featured in the Ms. Love column will appear under a pseudonym to protect privacy, and may be edited.





An ongoing series of articles about Walter Kiver who lived with Muscular Dystrophy (MD); as did his son, daughter, and grandson. Articles are written by Joan Burrows, Walter's wife, in memory of her beloved husband who passed away in 2001, to honor his legacy of living life fully and helping others while facing his own challenges.

Dealing with the Coronavirus: Living Alone at Age 88

By Joan Burrows

Learning to live with all the changes because of the Coronavirus has taken some getting used to. While I am grateful for the many good things in my life, there are still many challenges. I share my thoughts and experiences in the hopes that they will benefit others.

I have a small group of friends who are very caring people. They call, set up Zoom, bring flowers, food, and chocolate, and they offer to shop for me and.... and...! Sometimes when the warm sun is on my terrace, we sit 6-feet apart, eat a sandwich and chat. I enjoy watching my birds even more than before. I miss my cat, age 17, who died at the end of February. I wish she were here to pat and care for and love. I have a car I can drive if I want a change of scenery. The trees are magnificent, and traffic is very light; it would be good for my car and for me. I did this couple of times, but since then I have been at home and fallen into a pattern. I need to work on that!

I have mounds of papers and pictures from thirty years of working on the local Commission on Disability that need organizing. I have some 80 plus years of pictures of family and friends that need the same. Sometimes I get ambitious and sometimes not. TV and games and searches on the computer take over at times. But then, before this virus, I did a lot of both too. I love to garden, but my back does not. I do a little at a time; mostly on my terrace. I will be glad when the weather is warm enough to plant new flowers and for the old ones to bloom

with color and cheer.

I miss teaching my friend piano. I miss seeing my daughter who lives in the city. She comes out to work on Sunday and makes time to visit with me. I miss our commission meetings, and I miss the spontaneity of going grocery shopping, to the hardware store, the cleaners, the bank, the post office, to get a haircut when I want or need to. These people are also my community of friends.



I have my social security check, food and friends so I consider myself fortunate. Although I don't sleep or eat as well and I eat too much chocolate, these are small problems in comparison to what some are experiencing. I worry about others and I try to do little things to bring cheer into the lives of others. I have made a few more donations for food, children and to help animals.

I have almost stopped watching CNN; I used to watch it a lot. There is just too much talk of the virus; it takes over my day, my thoughts, my life. It is too much and too depressing. There are some good things happening and good people doing good things, but we hear very little of that.

My son and daughter both have to go to work at hospitals in Boston. My grandchildren are teaching, working, learning at home. For one, a graduation from college has been postponed. My sister who is age 91 lives in a retirement

community in NC which has strict limits. She can go for a walk 6 feet apart; otherwise she is limited to her apartment. A friend who is living in a local residential facility cannot go out at all. I know others who are depressed and lonely. I worry about them all.

I guess there is no good way to deal with this situation. Everyone needs to find their own way – with help. One way I've been dealing with it is by doing things for others; it helps them and me. I have been knitting little baskets and bags and putting in little treats, calling and e-mailing friends and family. As part of a program by my state representative, I make calls to seniors who live alone. A few have been chatty which is nice.

I have noticed that people who previously walked by me without a look or a hello, now wave from a distance and say "hi" as they walk by my terrace. Maybe we can all become nicer to others! COVID-19 is a big price to pay for something that should exist anyway, but something good is happening. Maybe it will last and make the world a better place. Surely, something positive must come out of all this heartache and pain.

If my husband, Walter, were still alive, like the rest of us, I imagine he would be frustrated at not being able to go shopping, eat at restaurants or go to the movies. He would still have been able to find enjoyment sitting outside and going for walks on good weather days. After all the years Walter spent in his room, he learned patience and coping skills that I believe would have been beneficial during this time. If Walter's PCAs did not come, I would have managed to care for him. But I think Walter's PCAs were super people and cared so much for Walter, that they would have come! I most certainly would be happier if Walter were here and we were going through this together.



Joan Burrows studied music in NYC and later taught piano. She was a nursery school owner, teacher, and music director. Joan began the Acton Commission on Disability with Walter Kiver. She is a caregiver for people with disabilities and seniors.

Coronavirus Conundrums

By Raymond E. Glazier

PCA consumers, consumers' surrogates, and their PCA workers alike have many concerns about the ongoing pandemic and its immediate, vital impact on their health, safety, and wellbeing. Pretty much by definition, PCA work is a hands-on proposition that can't involve social distancing.

Things pretty much boil down to a single overarching question: How to keep everyone safe in this public health emergency situation? MassHealth has taken some unprecedented measures to help.

- For consumers with PCA coverage shortages, MassHealth is authorizing its registered Home Health Agencies to provide services to PCA Program consumers within the overall limits of the MassHealth has provided each PCA with a letter identifying the bearer as an 'essential worker' providing home-care services who is exempt from stay-at-home emergency orders and travel restrictions. Click [here](#) to download the letter that was provided by MassHealth for PCAs/Workers to show they are an essential employee.
- In case a PCA needs to work more than 50 hours in a given week to meet a consumer's needs, perhaps due to the unavailability of a fellow PCA, MassHealth is waiving the weekly overtime limit.
- For consumers with PCA coverage shortages, MassHealth is authorizing its registered Home Health Agencies to provide services to PCA Program consumers within the overall limits of the consumer's approved PCA

weekly service hours. Call the MassOptions hotline at 1-844-422-6277 to receive contact information for registered agencies in your area in order to obtain home health aide services.

- For consumers unfortunate to have tested positive for the coronavirus but fortunate not to be hospitalized, MassHealth is providing PPE (personal protective equipment like gowns, face masks and gloves) to their PCAs to keep them safe and healthy on the job. The consumer or surrogate, with COVID-19 test documentation in hand, should contact the MassHealth LTSS Provider Service Line toll-free at 1-844-368-5184; press 1 for members, and then press 1 to get to the PPE program representative.

Because PCA candidates have not been free to travel for interviews and are reluctant to visit strangers' homes, recruitment of new PCAs has become nearly impossible. Consumers and surrogates accessing the Search for Workers function of the online Mass PCA Directory (<https://www.masspcadirectory.org/>) increasingly receive the message "No Worker Found." The same thing often occurs these days on <https://www.rewardingwork.org>.

And consumers in need of a new PCA would be just as reluctant to receive a parade of PCA candidates into their homes where they are self-isolating, if that were even likely. PPE-like gowns, masks, and gloves, as well as disinfectant wipes and hand sanitizer are not reasonably available to the general public, so PCA consumers and workers must get inventive about coronavirus transmission prevention measures. Here are some tips that offer at least some degree of protection:

Gloves: First of all, thorough, frequent hand washing with a detergent soap like the one you probably have at your kitchen sink is vitally important and can reduce the anxiety level in the absence of gloves; exam gloves are in short supply and increasingly costly. Yet there are certain embarrassingly messy personal hygiene situations that absolutely call for gloves. Thin plastic film food service gloves provide a modicum of protection; these gloves are readily available online and are very inexpensive.

Gowns: An old long-sleeve nightgown or smock (or a short-sleeve one over a long-sleeve shirt), if washed after each use in hot water with strong detergent can be of use. In a pinch, a trash bag with holes cut for head and arms, worn

over an old long-sleeve shirt (laundered as above), can be an emergency disposable gown.

Masks: There are a goodly number of online tutorials that demonstrate how to sew face masks from old clothes. If like me you don't sew, there is an easy shortcut. Cut the sleeves off an old tee shirt, the heavier the fabric, the better. This can be pulled down over the top of the head, snugly covering the nose and mouth. Be sure to wash after each use in hot water and strong detergent; adding bleach to the wash will help.

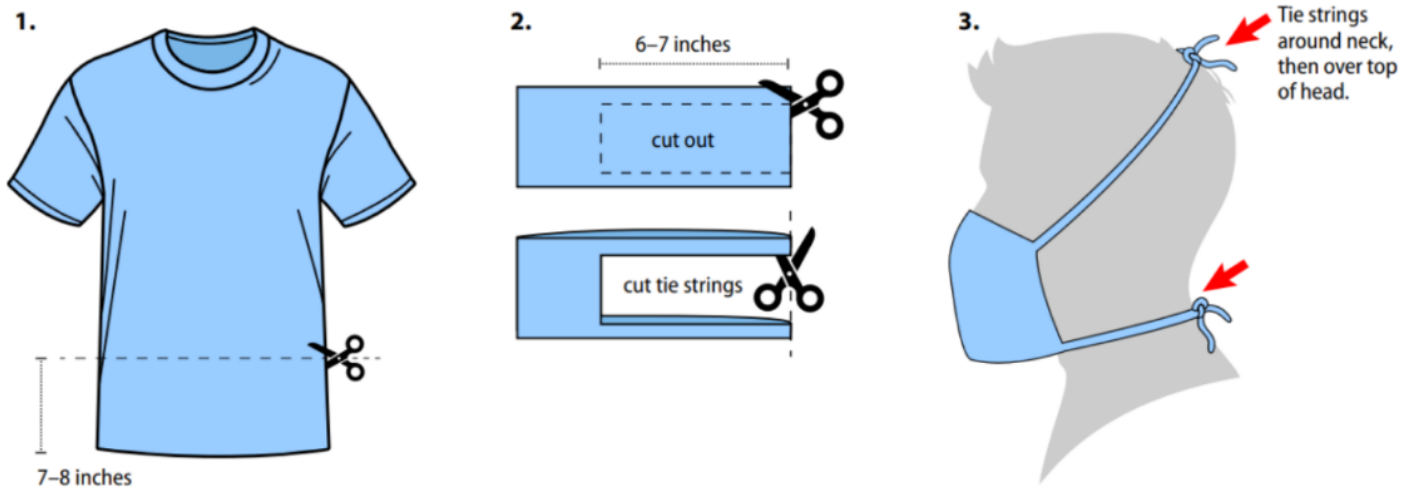
T-Shirt Mask - No Sewing

Quick Cut T-shirt Cloth Face Covering (no sew method)

Materials

- T-shirt
- Scissors

Tutorial

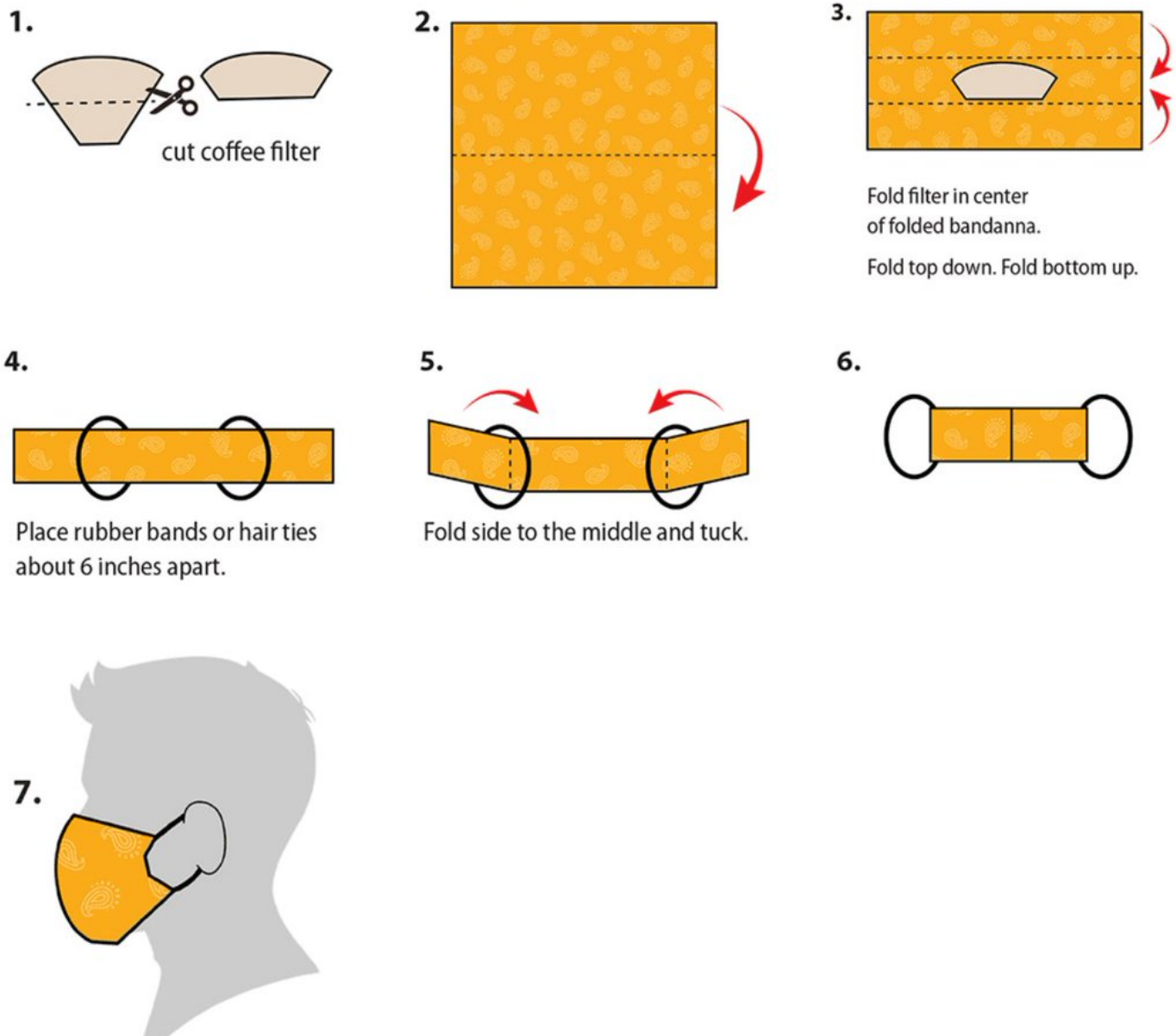


Bandana Mask - No Sewing

Materials

- Bandana (or square cotton cloth approximately 20"x20")
- Coffee filter
- Rubber bands (or hair ties)
- Scissors (if you are cutting your own cloth)

Tutorial



Disinfectant Wipes: These handy items are in very short supply, yet they are now very necessary for wiping down surfaces, doorknobs, controls, and handles where the coronavirus can linger. If you have, or can obtain rubbing alcohol (preferably 70% or higher), you spray the rubbing alcohol directly on suspect surfaces, or you can make your own disinfectant wipes by spraying the rubbing alcohol onto paper towels or soaking clean old rags with it.

Hand Sanitizer: This is another currently hard-to-find product that you can make at home. Rubbing alcohol (again preferably 70% or higher) can complement frequent, thorough hand washing noted above, but not be a substitute for that. However, it does have a drying effect on the hands. If you are able to find pure *aloe vera* gel and can obtain grain alcohol (95%) at your

liquor store, mix one part *aloe vera* gel with two parts grain alcohol for a more hand-friendly sanitizer. Shake the bottle vigorously to blend the two and sake again before each use.

Keep yourself safe from COVID-19 and stay healthy during this coronavirus pandemic.



Raymond E. Glazier, Ph.D., has decades of personal and professional experience with PCA issues both as consumer and researcher. He is the founder and principal of disAbility Research Associates, Belmont, MA. Please email questions or suggestions for future columns at raymondglazier@gmail.com



The Opinion Corner

What Passion Can Do

By Sandy Alissa Novack

The news started coming in fast and furious about the pandemic – on television, the internet, in newspapers, from friends and family. Everywhere we turn, there are reports of case counts and death counts. When I started hearing about webinars to talk about the coronavirus and people with disabilities, I got excited and registered right away. Out of all the other news slants and angles that were being addressed, I was heartened to know that issues related to the impact of coronavirus on this population were being addressed.

The webinar presentations didn't disappoint. I find myself thinking, if we could

harness the joint concerns of everyone who participated and be political and social advocates for people with disabilities, we could change the trajectory of the pandemic. This is why I am sharing my notes from two such webinars, which are referenced in this issue's articles: **“The Women's March, Coronavirus, and People with Disabilities”** and **“The American Association of People with Disabilities, the Coronavirus and Medical Rationing.”** Additionally, I attended the National Consumer Voice for Quality Long-Term Care and COVID-19 webinars, referenced in an Info Brief in this issue.

Make no mistake, the situation for people with disabilities in this pandemic is intense. Every voice is needed. After you read the articles, I am asking you to join me in being an advocate for disability rights; our voices are especially needed during the pandemic. I am asking you to learn about current issues and to take action. Consider emailing your legislator or writing a letter to your local paper. Add your voice to the discussion on how writing good policies requires having people with disabilities at the table to offer critiques and awareness of how certain policies would negatively impact people with disabilities. Offer to be one of the people sitting at the table. Contribute your ideas for better options and better practices that are better for people with disabilities. In addition to helping during the pandemic by staying home to flatten the curve, you can also jump into action – for yourself, for your loved ones, for your community – all while staying at home.

As a long-time consumer advisor on the Universal Access Advisory Council at Beth Israel Deaconess Medical Center, prior to the pandemic, I was already involved in providing a disability perspective to improve the hospital experience for all patients. Participating in the pandemic disability-focused webinars led me to listen to a presentation about Crisis Standards of Care – guidelines hospitals will use during this pandemic that govern how decisions get made around the allocation of limited medical resources. I have some points regarding people with disabilities and elders that I will bring up at a follow-up meeting with this hospital group.

Given my professional background as a geriatric social worker and my concern for relatives and friends who have needed long-term care, I chose to listen to a series of webinars on long-term care and the pandemic. With the high number of coronavirus related cases and deaths in long-term care facilities, my passion

led me to apply to serve on a short-term commission that is charged with looking into these issues. Even if I am not selected to participate on the commission, I won't be too concerned; I will still have my passion. I will still find a way to make a difference on these long-term care issues. Passion can do a lot. What pandemic issues are you passionate about? While staying safe at home, what action can you take? What is the “something” you can do to make a difference?



Sandy Alissa Novack, MBA, MSW is a social worker, and consumer advisor on the Universal Access Advisory Council at Beth Israel Deaconess Medical Center.

The Women's March, Coronavirus, and People with Disabilities

By Sandy Alissa Novack



DISABILITY JUSTICE IN THE TIME OF CORONAVIRUS



webinar
wed. april 1.
8PM eastern



Our webinars include closed captioning and can be found on YouTube.

During this pandemic, are you or a loved one feeling isolated and out of touch with the world? Are you staying home as much as possible because you are at risk with disabilities or chronic health issues? Some interesting webinars have been offered since the pandemic started that are available by phone or computer with no fee. The Women's March sponsored a webinar on April 1, entitled "Disability Justice in the Time of Coronavirus." Here are some notes from the webinar. *(click on the "Disability Justice" image, which is linked to the webinar on YouTube.)*

The speakers named some realities they are seeing: Many of those in power are more concerned about their wallets than the public and we are living amongst people for whom it is acceptable that people with disabilities are dying. We need to acknowledge that when crises happen, everyone does not experience them equally. Immigrants, elders, and people with disabilities frequently experiencing them more severely. They reject that anyone's life is expendable.

Ableism was defined as the structural mechanics of what society does; who is valued, who is not, and it does not include anyone who is disabled or has chronic illness. Disability concerns were discussed as a justice-based and not a rights-based movement: people are whole the way they are, there is a strong focus on interdependence and not independence, and everyone should have access to what we are working toward (called collective access). One speaker

talked about some of the coronavirus issues. “We are hearing subjective definitions of who is productive and who should get medical treatment... But we should protect one another, and everyone should have access to resources... protected from being pushed out of lines to get what we need with the pandemic.”

Speakers spoke about the irony we are seeing in the pandemic that people with disabilities are keenly aware of:

- We have often been viewed as too lazy to go down to the store to get our own groceries; we want to order groceries online to be delivered or have aides go shopping for us. Since coronavirus makes leaving the house a health risk for everyone, non-disabled populations want grocery deliveries; sometimes competing with and squeezing out people with disabilities from booking deliveries. This is at a time when many of us are losing aides who shop for us because the aides have become ill with the coronavirus or because they are sheltering in place themselves.
- The disability community has a long history of fighting for the right to work from home. Many employers have resisted making this accommodation because they claimed the position required the employee to be in the office. Now that the coronavirus is here, many employers are providing technology and other resources that enable employees to work from home. Some employers are even considering allowing a segment of employees to continue working from home after the pandemic.
- People with disabilities have fought for academic classes to be offered online because of seizures or other health and disability related issues. With the pandemic, academic institutions and teachers have figured out how to offer all classes online for all their students.

In the medical sphere, the issues are just as provocative. People with disabilities and other marginalized identities are being pushed out of receiving medical care they need to survive the pandemic. Disability, economic and racial biases are playing a role in determining who is “prioritized” as worthy of having equal access to medical resources. There are some who think those with disabilities who are not employed and “producing” should be prioritized as less

worthy to receive medical care. One speaker spoke of how some doctors are reluctant to believe black women who say they have symptoms of COVID-19 and therefore, are not treated and have died. Similarly, the speaker continued, 25% of women living with lupus are black women, but some pharmacists are denying black women their lupus medicines because these medicines are needed by others who are prioritized as more worthy. These biased narratives cause harm and need to be changed to – all people are worthy and have intrinsic value because they are a human being.

One speaker discussed how some groups are using the pandemic as an opportunity to roll back the civil rights of people with disabilities. One example is, the U.S. Chamber of Commerce has asked for a waiver of the ADA for hiring people so employers can ask people about their health and disabilities. The speaker said, “We are not willing to waive our civil rights.”

Here are some suggestions the webinar speakers made for people who want to take action:

- Monitor the hashtag [#WeAreEssential](#). Post videos with this hashtag to our legislators, and have your loved ones and others contact their legislators, too.
- No one should be at the back of the line for medical care. Fight against rationing medical resources. Point out that focusing on only helping the young and healthy is against the law.
- Check in with friends and peers who may be dealing with fear and isolation.
- Be vocal about reminding people that the disability community pushed for paid sick leave and work-from-home accommodations. As is often the case, disability advocates push for laws and programs that benefit people with disabilities and these changes often end up benefiting all of society. Additionally, non-disabled people can quickly become disabled, so encourage members of the temporarily able-bodied community to be proactive about advocating for disability civil rights on many fronts.

- Do not hoard. People who are



living paycheck to paycheck or who have no paycheck coming in cannot stock up. They need essential supplies to be available when they can afford it.

- Do not buy what you do not need. Some have purchased items such as gluten-free foods because they prefer them, while others need these resources for health reasons.
- Be constantly vigilant and speak up when you notice that marginalized populations are not being treated well.
- Legislators and others must not speak as experts on what marginalized communities need. Rather, members from these communities should be invited to the table to be listened to and have a voice in drafting policies that will affect these individuals.

Thanks to the Women's March for being one of the first organizations to address issues for people with disabilities in a webinar on the coronavirus!

The American Association of People with Disabilities, the Coronavirus and Medical Rationing

By Sandy Alissa Novack



On April 3, the American Association of People with Disabilities (AAPD) hosted a thought-provoking webinar on the pandemic, disability discrimination, and medical rationing. In this article, I am sharing my notes in case you missed this important talk. Crucial takeaways are: no one should be using stereotypes about disabilities to deny anyone care and everyone must have an individual medical assessment. One speaker said it is a reflection of our national character that no one is left behind during the coronavirus.

Do disability laws apply to the health care system? Yes. There can be no discrimination against people with disabilities. Medical providers have a history of underestimating the abilities of people with disabilities. It is imperative, therefore, for providers to act on the best objective evidence based on an individual assessment. A pre-existing condition does not rule someone out for getting treatment for the coronavirus.



Examples of how some states in this country are showing bias in their policies toward people with disabilities were discussed. For instance, one state had a triage plan which singled out people with intellectual disabilities, brain injuries and other diagnoses from receiving treatment or having a ventilator. They were excluded because

their lives were viewed as less valuable than other lives. Another state developed a policy where one's ventilator could be taken away from them if they were deemed less worthwhile to live than someone healthier. Policies were not about if people could recover from the coronavirus, but about how we value the lives of people with disabilities even without the coronavirus.

The Office of Civil Rights had to act quickly and set protocols to get ahead of policies that would preclude people with disabilities from getting the medical care needed during a pandemic. They said the law prohibits these kinds of state policies and they had better fix their policies before the pandemic costs more people with disabilities their health and lives. After all, hospitals want and depend on these concrete guidelines that states develop.

One speaker talked about the meaning of how medical providers rate the quality of life of a person with disabilities: it is really a measure of ableism and not the quality of life of any person with a disability. Research has shown that people with disabilities explain their lives as quite well, but the health care field views it as much less than well. So objective evidence is needed. We need guardrails for policies as biases are persistent. We can't have people with disabilities' pre-existing diagnoses dictate if they can have coronavirus treatments. Biases really come into play when judgments are made about prognosis over a long period.

Just because disability is a factor does not mean that other factors should not be considered. For example, one person who had cystic fibrosis was presented as someone who might have been excluded from treatment because of bias. But on an individual assessment the person had a record of good lung capacity, making them a good candidate for treatment. Reasonable accommodations come into play too. For instance, an ASL interpreter may be needed to help people who are Deaf during the pandemic just like in non-pandemic times. Or if a standard protocol is to be on a ventilator x number of days, a modification may be needed for someone with disabilities; perhaps adding more days needed on the ventilator.

One speaker shared a simple, but powerful example of what family members

can do to help a person with disabilities receive medical care. This may be especially important if it's someone with intellectual disabilities or impaired communication. Before going to the hospital have someone write on their body, "I want medical treatment." Do whatever you can to be absolutely clear that you know your rights, and someone is watching the situation.

Closing thoughts:

- Policies about medical rationing should be required and made public for transparency.
- Medical providers must have a better understanding of how policies and individual assessments impact people with disabilities. We should start right away to make medical providers aware of these issues in trainings. There is some ability to do current bias and awareness training, but we also have to continue this work after the pandemic.
- Data has to be collected. For example, who gets the ventilator? How does disability factor into that? Did a person with disabilities die because they never got a ventilator or did a person with disabilities get a ventilator and die anyway?
- Prevent hospitalization to begin with. If a person with disabilities has a PCA or other caregiver, these people need personal protective equipment so they don't infect their client or get infected. People with disabilities cannot stay safe at home if they cannot get the supplies they need. They need cooperation from the state, medical providers, and others to get what they need to stay safe at home.
- Bioethicists need to be on teams that make decisions on policies and care. The bioethicists and people with disabilities live in separate worlds and don't overlap. Progress can be made if bioethicists are open to listening to disability issues.
- Guidelines and protocols best protect hospitals from liability. Hospitals need to have people with disabilities at the table as guidelines and policies are developed.
- PCAs: The fundamental goal is for medical providers to provide life-saving treatment. Accommodations to have a PCA with a patient while

they are in a facility is reasonable and possible. The facility should have disease control policies in place and require PCAs to comply with them.

- Take steps for people with disabilities to get the medical care they need before going to the hospital.
- Stay in contact with your disability community and your local health care community, such as your local independent living center. The Boston Center for Independent Living has been offering forums on the pandemic situation.
- No matter which state you live in, if you are an advocate you can approach your state legislators and find out what protocols they are working on and make sure they are involving people with disabilities to establish these protocols. The sooner people with disabilities are involved, the more influence they will have.

“...think about the world we want to live in after the pandemic and act accordingly now.”

During one presenter’s closing statement, she talked about how heart-breaking it is to hear the fears of people with disabilities and their families. She advised listeners to "...think about the world we want to live in after the pandemic and act accordingly now." The whole presentation was well done, but this part was especially well said.



Sandy Alissa Novack, MBA, MSW is a social worker, and consumer advisor on the Universal Access Advisory Council at Beth Israel Deaconess Medical Center.



The National Consumer Voice for Quality Long-Term Care and COVID-19

"Consumer Voice" offers a robust information and resources page for Coronavirus related issues in long-term care facilities. They are hosting a weekly series of joint webinars with the Center for Medicare Advocacy, Long Term Care Community Coalition, and Justice in Aging. The webinar series addresses COVID-19 issues as they relate to long-term care facilities. If you are concerned about elders and younger people with disabilities getting ill at long-term care facilities from coronavirus and dying, these webinars provide the most current information.

Webinars are free and can be accessed by computer or phone. To view the Consumer Voice Covid-19 information and resources page, including recordings and slide presentations for all previous webinars, visit:

<https://theconsumervoice.org/issues/other-issues-and-resources/covid-19>

Attorney General Maura Healy on Disability Rights

The Attorney General Maura Healy has provided guidance on the Rights of Disabled Persons to Accommodations During COVID-19 Crisis.

“The COVID-19 pandemic has created unique challenges for people with disabilities. Some disabilities increase the risk of infection and severity of illness. Additionally, measures taken to prevent the disease from spreading have created new barriers for people with disabilities to access needed goods and services. This guidance provides some examples of how our civil rights laws protect the rights of people with disabilities in the context of COVID-19.”

[Click here](#) for the guidance document.

Whether you are an advocate, resident, family member or friend, there is beneficial information in these webinars, such as:



- Infection control issues even before the pandemic, including handwashing.
- Staff and second jobs, staff and sick pay.
- Medicare waivers during the pandemic.
- How to speak up and advocate.
- And much more!



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Spaulding Rehabilitation Network Liaison:

Colleen Moran
<http://spauldingrehab.org>



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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

The ***Disability Issues*** newsletter is a free and independent publication. It is published quarterly and shares current information about the world of disability, new initiatives, and other helpful information to the disability community in Massachusetts.

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Our mailing address is:

Disability Issues c/o Spaulding Hospital Cambridge, Attn. Human Resources,
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