

Creative Works

Disability Culture 20/20

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Abstract

In spring 2020, the world changed from the Coronavirus pandemic. My wife and I have been mostly staying at home since then. We've spent a lot of time on social media, communicating with our friends and family. And I've been working on a book about Disability Culture. It includes poetry, mostly my own; and many examples of what other people are doing to contribute to and celebrate Disability Culture. This chapter from the book draft is called *Disability Culture 20/20* and is about disability culture activists during this pandemic.

Keywords: pandemic, poetry, activism, coronavirus, disability culture

SONATA IN THE LINGERING KEYS OF LIFE

Steven E. Brown © 1996

I.

Found Jim Morrison wailing at me on the radio last night:

"C'mon, baby, light my fire,"

Soothed-voice, throaty, alive,

except, of course, he is not...

1969, a magical year in so many of our lives,

A number tipping the consciousness only after meditating upon those thirty years gone,

except, of course, they are not quite thirty years gone...

Morrison, Joplin, Hendrix,

Candles dying through flames bright.

Memories intense,

Lives vivid,

Whole notes remain.

II.

Idol conversations?

Wordphrases streaming daily now

If only I would listen--

But I am.

Voices searching, seeking me out,

Not those of gods and goddesses,

but frail and mighty warriors.

Sometimes screaming from beds
as tightly bound, as completely free,
as prisons.

Sometimes screaming from conferences,
festivals of the soul;
An only outlet
for many of thy voices.

III.

Ali Baba's magic words barely open
any doors
for my people,
whose voice do we have?
the lame and the halt,
the biblical meek,
the Reagan rejects
roaming the streets.

Some slaves of old
Found comfort in the words
of glorious spirituals
and glory in the future
of the spirit.

Their gateways
handed down
to the trodden
of a new century.

Shimmering hope--
heaven unbridled by earthly restrictions.

IV.

The greatest compliment you could once bestow:

“You don't seem any different to me”--

“In my eyes you are normal”--

meaning you are like me
somersaulted into an insult
while you weren't looking.
What makes you,

white man, black man,
red woman, yellow woman,
brown child, rainbow race,
Believe that putting two feet on the ground,
Waving two arms in the air,
Having a face unmarred except caked,
Thinking in a straight line
Or famed, artistic, eccentric convolution
Spells normality,

Meaning if you are not like me

You had better want to be like me...

Normalized?

V.

Rocky, jagged outcroppings

Snagging us.

One-liners dropped into a history book or two

Ed will one day make it into your seventh-grader's notes

But Morrison, Joplin, and Hendrix I don't see replaced by

Zola, Zanella, or Follin-Mace.

VI.

The world has begun to give me

a gift of recognition of my poetry,

my zeal and carefully-planned idolatry.

Pain poems magnify, intensify

Perhaps they'll never rinse away;

Perhaps my purpose, or a part of its part,

Is to have this conversation

To hear this voice

which has found others' listening

and others' straining to hear and

others' needing to hear

and face their own fear.

VII.

Naked truths don't lie...

Still who will believe this difficult excursion?

Not paint it with sugar-coated

candied explanations

of good-heartedness,

god-plannedness?

Who will just listen

nod their head in acknowledgement, contemplation, recognition?

Who will not listen

rush to aggravation, defense, censorship?

“Break on through to the other side.”

VIII.

BREATHING

My poetry,

like my body...

survives.

Disability Cultures

There is not one Disability Culture, but many. I've tended to focus on the big picture of Disability Culture, both because I had to start somewhere and because that has been a way to convey its existence, which is still largely unknown, or a mystery, to many. But, like disabilities and cultures themselves, Disability Culture is dynamic.

In spring 2020, the world changed from the Coronavirus pandemic. Lil and I have stayed indoors most days, getting out every week or so in our van, mostly to keep it running and once in a while to go to the bank, because we have yet to be able get cash online. We have a wonderful person doing grocery shopping for us, and before that friends and neighbors offered. We're both in what is considered a vulnerable group: over 65, with pre-existing conditions. We have been cautious and careful. We can do this because we have the privilege of being in our own home (well sort of, we do rent), we have steady (though hardly heady) revenue from retirement funds and are able to pay our bills. And, unlike many of those sheltering at home, we have and like each other. We know we are privileged.

At the same time, our lives have changed. We spend far more time on social media than we ever did and are blessed to communicate with our grandchildren and their family via platforms that support audio and visual communication. We are privileged.

But our privilege has not stopped our friends from dying—a plethora of deaths in the disability community, some directly from the Coronavirus, some impacted by it, and others from diverse causes. Our community is scared to go to hospitals because we are often so badly treated in them, sometimes to the point where we know hospital staff would prefer to see us dead (I speak from personal as well as anecdotal experience here). We listen to news stories that describe how resources might be better used for younger, “healthier” people. We have good reason to be afraid, not only of the virus, but of our own society.

In this time, many communities of disability advocates have rallied. In one such example, in mid-May, Krip Hop and the Longmore Institute co-hosted a livestream concert, the “Corona19 Artistic Flow Benefit,” featuring 16 hip hop artists including voices and visual art from Tanzania, Brazil and the U.S. for “The Reality Poets, young brown and black men in New York who use their art to heal from assault, and Warriors on Wheels, a disability organization in Detroit currently committed to pandemic grocery deliveries” (Sullivan, 2020).

In writing about this event for the *San Francisco Examiner*, Denise Sullivan declared, “Leroy F. Moore Jr. is not one to let a physical disability nor a pandemic get in the way of fulfilling his destiny as an artist, a disability rights educator and an activist” (2020).

When I began this book, before we knew about the Coronavirus, I started writing about U.S. activists who describe themselves as Generation ADAers. One of those younger folks is a black woman named Vilissa Thompson, who created the innovative “Ramp Your Voice” website (<http://rampyourvoice.com>). Vilissa wrote that she’d use “Ramp Your Voice” to: “promote empowerment, education, inclusion, and self-advocacy for disabled people across the United States and abroad” (*Ramp Your Voice*, n.d.). She’s been doing this with posts like, “[#DisabilityTooWhite: Making the “Good Trouble” in Advocacy](#)” in which she also created the Twitter hashtag “#DisabilityTooWhite.” She describes below why she did this:

Alice Wong, a dear friend and fellow advocate, shared an article about disability and beauty that showcased the “standard” imagery of beauty for disabled women: disabled White women. In Alice’s tweet and response, she shared her frustration regarding the lack of diverse representation about who we are as a collective group, and I and many others, chimed in with similar sentiments. While I was tweeting my thoughts, an idea popped into my mind, and I started writing #DisabilityTooWhite in my tweets (Thompson, 2016, para. 2).

I didn’t know of Alice Wong, mentioned in the above quote, before moving to the San Francisco Bay Area in 2014 but I quickly learned about her. In 2015, when we in the U.S. were thinking of different ways to celebrate the 25th anniversary of the signing of the ADA, Alice conceived the Disability Visibility Project (DVP), which she describes as: “an online community dedicated to creating, sharing and amplifying disability media and culture” (Wong, n.d.). The first entry under “What Does the DVP do is: “**Believes** that disabled narratives matter and that they belong to us” (Wong, n.d.).

Alice also has the distinction of being the first person to visit the White House robotically. Since she doesn't travel much, she had an opportunity to visit the White House from California in 2015 and talk with President Barack Obama via the technology of a telepresence robot (a remote-controlled, wheeled device that has internet capability and may provide both video and audio) as demonstrated in the photo below of the two talking (See Figure 1).

Figure 1

President Barack Obama greets Alice Wong, Disability Visibility Project Founder and Project Coordinator via robot during the Americans with Disabilities Act 25th Anniversary reception in the Blue Room of the White House, July 20, 2015. Obama White House Archive.

<https://obamawhitehouse.archives.gov/photos-and-video/photo/2015/07/president-obama-greets-alice-wong-robot>



With the onset of the Coronavirus, Alice has roared full steam forward in sharing stories and in being clear about the impact of this devastating pandemic for people with disabilities. She writes in “Disabled Oracles and the Coronavirus,” that “disabled people know what it means to be vulnerable and interdependent. We are modern-day oracles. It’s time people listened to us” (Wong, 2020).

In this post she eloquently shares part of her own story:

Even before the coronavirus pandemic, systems have always tried to kill and oppress marginalized people.....These crises and assaults reconfirm who is considered disposable and unworthy of assistance, resources, attention, and treatment.

I use a non-invasive form of ventilation called a Bi-Pap. My vent is part of my body—I cannot be without it for an hour at the most due to my neuromuscular disability. I have sleep apnea and cannot properly remove carbon dioxide from my body without the Bi-Pap which can lead to respiratory failure. I am so dependent on my ventilator that it is attached to my wheelchair where it draws continuous power from my chair’s battery—it is part of my cyborg being.

So many people see me and presume that I have a poor quality of life because I have a tube attached to my face and that I sound different. I refuse to allow the medical industrial complex [to] reduce me to my comorbidities, risk factors, and inability to perform X number of activities of daily living. (Wong, 2020)

Wong’s insistence on leading a life well lived reminds me of our friends Jim and Sheryl Tewksbury, who we met in the early 2000s. At the time, they had an idea that every single person, particularly individuals who experienced cognitive disabilities and who wanted a college education, ought to be able to get one. They believed there was a way to do that and their vision became Global Campuses Foundation (GCF), which celebrates its 20th anniversary in 2021.

The GCF mission is: “facilitating collaborative learning opportunities for adults who experience disability” (“About Global Campuses Foundation,” n.d.). One of the unique aspects of GCF is the focus on student ownership of their education or as put on the GCF website:

GCF’s educational philosophy and methodologies promote campus members taking ownership and stewardship of their campus. Global Campus participants are the

creators and producers of their educational experiences and take on leadership opportunities as faculty, students, and administrative staff. (“About Global Campuses Foundation,” n.d.)

Another unique aspect of GCF is its international scope. GCF intentionally facilitates a worldwide campuses network that is designed to promote cross-cultural education and exchanges. As I write in late 2020, there are 11 campuses in Vermont, one campus in New Hampshire, and seven in Northern Thailand, with ongoing talks for expanding into neighboring countries continuing even in the age of the Coronavirus.

During the pandemic, a week after suspending in-person classes in the U.S. in early March, GCF provided distance learning classes for 200 participants. The U.S. participants were also involved in some classes and exchanges of curriculum and other information with their Thai counterparts. In Thailand itself, there has also been a lockdown since early March. Many campus participants returned to their homes throughout northern Thailand. In Chiang Mai, home of Chiang Mai University and the base of GCF in Thailand, Global Campus Chiang Mai (GCC) facilitators, Kachakorn Thaveesri (Ka), GCF Regional Director for Southeast Asia and Yutthaphon Damrongchuensakun (Non), GCC Director, both of whom have disabilities themselves, have gathered and delivered face masks and sanitizers to GCF campus leaders in other cities and to villages in rural areas. In a recent report, Ka and Non talked about receiving over 100 bags with fresh vegetables and getting ready to distribute them.

Non added “We are all very grateful that GCF values and supports leaders with disabilities and our activities to be a learning society in the culture of disability in Thailand.” (“Global Campus News,” 2020).

Back in the U.S., citizen of the world, Petra Kupperts, originally from Germany, but who lived in many different countries and cultures before finding herself as a professor at the University of Michigan, describes herself in part as a “Disability Culture Activist.” Kupperts who is an inventive artist/activist/scholar, community performance artist, poet, writer, and creator, was presumptively diagnosed with the Coronavirus in early March 2020. Kupperts, who often shares her life and activities via Facebook, had already begun creating more virtual platforms. At the end of April, recovered from her bout with the virus, Kupperts did a video

interview, “PERFORMING IN VIRAL TIMES,” with Amy Sass of the Ragged Wing Ensemble video series, “Moment 2 Moment.”

In the interview, Kuppers shares, “coming up with other ways of doing it [creating art/theater] and having as many people as possible involved in the creative process that is what is at the heart of my work” (Kuppers and Sass, 2020).

In discussing her latest poetry book, *Gut Botany*, which explores in part recovery from sexual assault, Kuppers addresses both her work and current times:

“so much of healing from assault is about being okay with other humans again and this is something we’re all gonna face you know when this, when this, pandemic gets to a place where we can be released from sheltering in place which I imagine many of us are doing, I’m doing right now, we will have to find ways of healing ourselves from being afraid of the other person and yet also being aware of what it means to be someone living in the 21st century, someone who lives in a world that has viral loads, toxic loads, you know, all the kinds of things that some of us have been able to ignore for long periods of time but many others have not you know so we hopefully will all emerge as more aware and so a lot of my healing journey is about being aware of what it means to reach out towards the other... (Kuppers and Sass, 2020)

In further exploring related themes, blogger extraordinaire, among many other roles, Meriah Nichols, who has multiple disabilities, wrote in a spring 2020 blog entry, “It’s Like We are in Timeout,” that the pandemic:

happened because the world is intrinsically interconnected but refuses to acknowledge it.

It happened because we have enormous disparities between the rich and the poor, we have a profit-based healthcare system and rampant ignorance....

We have been valuing money and work over all else....

The roots of global change happen on a local level, the ripple is generated from the core, and the core of every human being is our own self, which is exactly who we are now required to spend an inordinate amount of time with....

This pandemic will push us into new directions whether we want to go or not.

We are going to figure out how to come into our own worth – slip into our authentic power and be who we really are.

Because I think that fundamentally changing who we are and how we live is ultimately going to be the only way we can truly get out of Time Out.

That's such a tall order: because it involves love, authenticity.

Honesty.

It involves cultural shifts, education, systems of care, economic justice, rights.

It means being still and reaching in.

But I have confidence that tall order or not, we can do it.

This is, I believe, a part of our evolution, it's becoming more of who we were always supposed to be. (Nichols, M., 2020)

There are so many more examples of ongoing activities in the spring of 2020, including those of disabled activists and Disability Culture promulgators. This is one reason why this book will not be an end point, but a starting one for many and a resting and/or re-creating one in the middle of the process and creation of Disability Culture for many others.

I choose to leave this chapter with the final verse of my poem that opened this chapter, which I find uncannily timely, though the words were written over 20 years ago:

BREATHING

My poetry,
like my body...
survives.

Historian **Steven E. Brown** is a retired Professor and Disabilities Scholar, Center on Disability Studies (CDS), University of Hawai'i (UH), and Co-Founder of the Institute on Disability Culture. Brown has published many articles about disability rights and disability culture and is a national and international speaker.

His books include *Movie Stars and Sensuous Scars: Essays on the Journey from Disability Shame to Disability Pride*; *Surprised to be Standing: A Spiritual Journey*, and *Ed Roberts: Wheelchair Genius*, written for Middle Grade ages. He is also a co-editor of the anthology, *Rethinking Disability: World Perspectives in Culture and Society* (2016). He has presented on disability rights and culture throughout the U.S. as well as in Canada; Germany; Hungary; Korea (via remote video) Japan; Norway; Saipan; Sweden; Taiwan; and Thailand.


Brown created the UH/CDS online courses: “Disability History and Culture: From Homer to Hip Hop,” and “Disability Through the Ages.” Although he retired from teaching these courses, they continue to be taught by a successor.

After retiring from his full-time Professor position, he and his wife (and co-founder of the Institute on Disability Culture), Lillian Gonzales Brown, returned to the mainland, where Brown continues to write, advocate, and teach. He is currently working on a book about Disability Culture.

More information available at: <http://www.instituteondisabilityculture.org/>

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