References

WHAT IS DISABILITY CULTURE? DISCOVER THE PRECIOUS TREASURE

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Аннотация
2016 жылдың қыркүйек айында мені Тайбэй мүгедектерінің құқысы бойынша Ассоциациясы спонсор болған «Біз қалай бармыз, сондайымыз: жарымжан адамдардың мәдени құндылығына көзқарасы» тақырыбындағы конференцияға қатысуға Тайбэйгің шақырды. Конференцияның тақырыбы 1990 жылы мен жазған «Біз қалай бармыз, сондайымыз» экседен алған қазіргі кезеңде көзді аудару құқысы бойынша мүмкіндік туды.

Annotation
In spring 2016 I was invited to present at the September 2016 “We Are Who We Are: See Our Precious Disability Culture,” sponsored by the Taiwan Association for Disability Rights Conference, in Taipei, Taiwan. The title of the conference is a quote from one of my 1990s essays, “We Are Who We Are.” The conference presentation gave me a chance to both reflect on the beginnings of disability culture and to describe aspects of its present-day evolution.
Disability Culture has evolved over the past thirty years to becoming an amazing, vibrant, and useful concept—and agent of change—today. Before discussing what Disability Culture looks like now, I’d first like to return 25 years ago, to 1991, when I presented at a conference in Little Rock, Arkansas, in the U.S. At the conclusion of that presentation (later published as “I Was Born (in a Hospital Bed)—When I Was Thirty-One Years Old,”), I first publicly attempted to share what I meant by disability culture in the form of this poem, “Tell Your Story:”

**TELL YOUR STORY**  
Steven E. Brown  
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Tell your story  
Tell your story  
It may bump from the page  
like words of Braille  
sizzling in tales of blazing glory;  
it may glisten in the sunshine like the holy grail,  
so tell me a tale, even if it's gory,  
I'm yearning to hear you  
Tell your story.  
Have you heard  
'bout the man  
in the motorized chair?  
Found no ramp at the  
movie theater  
did he despair?  
No,  
just let them dudes lift him in there.  
Came back a few days later  
after somethin' greater  
brought with him a crew  
people in chairs just grew and grew,  
said they knew  
they'd be part of the view;  
no problem getting in,  
just lift and push and  
move those hunks of tin.  
The chairs, they weighed a-plenty,  
The ushers stressed and  
strained and got somewhat bented.  
Seeing the movie was not the goal  
changin' the stage was the whole  
they paid for gettin' in  
but that theater knew it sinned.  
People in chairs sealed their own personal stamp  
on that theater's shimmering new wheelchair ramp.
Tell your story
Tell your story
It may enrapture the floating air
like ASL singing its flair
it might even glisten like the holy grail,
but no one will set their sail
toward your tale,
even if it's hunky-dory,
unless you tell your story
Tell your story.

Once I knew a lady
got caught in a picket line
changed her whole design:
came back to her hometown
mission bound.
The hospital, it was ailing
cause it was failing to see
good health bound in the key of
phone lines hooked up with a TDD.
Said she'd seek cooperation or
she'd be mighty angry
might even round up folks and
stoke fires of insurgency,
gather signatures and seek publicity.
You know that hospital saw the light
put an end to the no TDD blight.

Last time I saw that lady
she was waving a sign
telling a TV station
she sure did mind
no news she could see
so why should she
listen to what they wanted her to be.
Now she knows how to stick it
with a picket and her
pockets have been lined with Advocacy.

Tell your story
Tell your tale
You will find you touch
with the sureness of a crutch
a framework for your dwelling,
a story needing telling,
steaming like a sunburnt trail
glistening like the holy grail.
Who will know what you entail
unless you risk the path to glory
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A Little History

Where did the idea of Disability Culture come from?

In the United Kingdom, in 1986, the London Disability Arts Forum held its first annual meeting where the late, great Vic Finkelstein delivered a paper called, “Disabled People and our Cultural Development.” In it he stated that Disability Culture: must develop spontaneously and creatively out of the collective experiences of disabled people. The development of our own distinctive culture to express a rounded picture of the reality of our lives will help us gain a place of our own choosing in the multicultural society. The celebration of difference, we will then discover, is the celebration of humanity, of being members of the human family [15].

Around the same time, in the United States, I read from cover to cover each edition of the groundbreaking magazine, Disability Rag. Editor Mary Johnson used the
phrase "Disability Cool" and a cartoon called "Disability Rat" featured a zealous character who pointed out abuse of handicapped parking spaces. Most significant for me was a 1987 article called "Emotion and Pride: The Search for a Disability Culture," in which Johnson interviewed Carol Gill, a psychologist with a disability, who discussed the need for a disability culture. Gill stated:

A disability culture movement can foster disability pride. It promotes pride in us; it allows us to project a positive image to the public. We renew each other and our strength through shared experiences and rituals. If we express our culture in some unified way, we're signaling; we're communicating what our values, goals, and identity are. Through our culture we can recruit people. When we present a strong image, it motivates people to want to belong. They want to be part of something that powerful [18].

By the late 1980s, I realized my passion had become Disability Culture. I perceived it as a way to combine my interests and background in history, reform, and culture. In the spring of 1990, I first publicly approached the idea of Disability Culture at the National Council of Independent Living annual conference in Washington, D.C.

I conceived a panel called "Speakers of the Independent Living Movement: Voices of Independence." Three panelists shared our stories for about forty-five minutes with an audience of a couple hundred people. We'd left half of our time for audience participation, but it was not enough. Everyone in the audience, it seemed, had a story they wished to share. The energy in the room and in the halls after we concluded was overpowering. There was no question that people were hungry for an abundance of stories--their own and others. Leaving the room, exhilarated at the response, conversing with co-panelist Judy Heumann (currently Special Advisor for International Disability Rights in the U. S. Department of State) I knew I wanted to keep exploring this area.

A few days later, in Tulsa, Oklahoma, at a state independent living conference, I facilitated a panel called simply "Disability Culture." A group of about six of us informally discussed this idea. Did such a culture exist? If it did, was it beneficial? What characteristics comprised such a culture? How did it affect our lives? How might it impact nondisabled people? Each participant wrestled with these queries and offered some tentative answers.

Later that year, I moved to California to work at the World Institute on Disability. I stayed there for three years and continued to think about the idea of disability culture while I worked at a Research and Training Center on Independent Living.

Between 1992 and 1994, several "firsts" relating to disability culture converged. The first Disabled Student Cultural Center opened at the University of Minnesota; Berkeley, California disability performance poet Cheryl Marie Wade received a National Endowment for the Arts Solo Theatre Fellowship; and I received the first national fellowship to research disability culture.

In late 1993, Lil (Lillian Gonzales Brown—my wife and partner) and I moved from California to southern New Mexico, where we created the Institute on Disability Culture [17].

One of the first activities of the Institute was publication of my Fellowship research as a monograph called, Investigating a Culture of Disability: Final Report. In an "Executive Summary," I wrote:

The existence of a disability culture is a relatively new and contested idea. Not surprising, perhaps, for a group that has long been described with terms like "in-valid," "impaired," "limited," "crippled," and so forth.... The Disability Culture Movement is running full steam ahead. While I write, and you read,
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multiplying numbers of people are creating rapidly increasing examples of
disability culture (pp. 8-9).
We also created our vision, and mission statement: “Promoting Pride in the
history, activities, and cultural identity of individuals with disabilities throughout the
world.” From that statement came our slogan, “Promoting Disability Pride.”

A Definition
In 1996, several years after beginning to talk and write about disability culture, I
published an article that included this one-paragraph definition:
People with disabilities have forged a group identity. We share a common
history of oppression and a common bond of resilience. We generate art, music,
literature, and other expressions of our lives, our culture, infused from our
experience of disability. Most importantly, we are proud of ourselves as people
with disabilities. We claim our disabilities with pride as part of our identity.
We are who we are: we are people with disabilities” [8; pp. 80-81].

Disability Culture and Independent Living
Why and how can Disability Culture be used to expand our lives, our advocacy,
and our ability to implement change? An initial response is simply if we do not
understand our own culture(s), how can we expect others to do so, let alone understand
why our culture is important to us? How can we show—and share—disability culture and
disability pride, unless we ourselves understand what they mean? About ten years ago,
Sarah Triano, once a student leader and the force behind the longest, continuing
Disability Pride parade, wrote:
Disability Pride is an integral part of movement building, and a direct
challenge to systemic ableism and stigmatizing definitions of disability. It is a
militant act of self-definition, a purposive valuing of that which is socially
devolved, and an attempt to untangle ourselves from the complex matrix of
negative beliefs, attitudes, and feelings that grow from the dominant group’s
assumption that there is something inherently wrong with our disabilities and
identity [32; pp. 476-77].

How do we show disability pride? Disability Culture? This is where we move
from the “talking head” portion of the presentation to sharing Disability Culture through
examples that demonstrate disability rights, history, talents and resources. Because
when we understand our culture(s), we can use examples from them to explain our
history, advocacy, talents, and resources, and why there are many reasons for us to be
proud of who we are—both as individuals and as a group. The remainder of this
presentation will therefore be focused on sharing examples of our Disability Culture.

Select Examples from Disability Culture

- Dance
- Comic Books
- Comics
- Comedians:
- Museums
- Movies
- Literature
- Music
- Protests and Parades
* Music Videos

**Dance:** The first disability dance troupe I came across was after I moved to California. It was the Axis Dance Company, which is described as a physically integrated dance company, which means it includes dancers both with and without disabilities. Axis was founded in 1987, and in the past 30 years has become internationally known.

A dancer who has worked with this company and many others is Alice Sheppard, a former professor of medieval studies. On her website, Alice writes:

I dance in pieces that explicitly question what we think we know about disability, dance, and the body. I also perform in pieces that address disability only by dint of my presence. I move in my wheelchair, without assistive technologies on the floor, and with my crutches and wheelchair together. Each of these modalities provides a new movement language, a new technique, and a distinct path to virtuosity. But they are each also a pure embodiment—a metamorphosis into a body with its own integrity and unique capacity for dance [25].

**Comic Book:** I have been using the comic book *Silver Scorpion* in my online classes for some time now. The creation of a group of American and Syrian youth in 2010, the Silver Scorpion is an Arabic, Muslim comic book hero who lost his legs in a land mine accident. I like the way this hero was created, the fact that he comes from another culture and that his story continued beyond the original comic book.

**Comics:** *Department of Ability.* Comics are also a part of the Disability Culture. This particular one I chose as an example a parent following a daughter’s wishes. As described on the Department of Ability website:

This gang of Superheroes, use their disabilities as their super powers.
Disabled children deserve to be represented in books and on TV in a positive way.
Without sad music in the background accompanying their story.
Children with disabilities are funny, exciting, happy, sad, mischievous, rude, caring.
Just like any other child.

I have created the Department Of Ability and am in the process of writing a comic, to be released in 2016/2017. I also hope to get it onto TV, so that ALL children, (not just ones with special needs) can watch enjoy, relate to, and realise that the child who lives down the street, is just the same as them. Just with a difference [33].

**Comedians:** Josh Blue, is an American comedian with Cerebral Palsy who won an American TV show called *Last Comic Standing*. I have used one of his appearances on the show in my courses when I can find the captioned version, which is sometimes available and then seems to disappear.

**Museums:** The Smithsonian National Museum of American History, which is one of a group of national museums in Washington, D.C., has featured disability-related exhibits for many years now. Several years ago, the Museum initiated an online exhibit called, “Everybody: An Artifact History of Disability in America.” On the webpage titled “Place” a historic and well-known poem, “Disabled Country,” by my friend Neil Marcus is featured. Neil doesn’t recall exactly when he wrote this poem, but it was sometime in the mid-1980s.
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“Disabled Country” (n.d.)
by Neil Marcus

If there was a country called disabled, I would be from there.
I live disabled culture, eat disabled food, make disabled love,
cry disabled tears, climb disabled mountains and tell disabled stories.

Then I am one of its citizens. I came there at age 8. I tried to leave.
Was encouraged by doctors to leave. I tried to surgically remove myself from disabled
country but found myself, in the end,
staying and living there.

If there was a country called disabled,
I would always have to remind myself that I am from there. I often want to forget. I
would have to remember...to remember.
In my life's journey I am making myself
At home in my country [22].

Movies: While many popular movies have included disability as a focus, the actual portrayals are not usually what disability advocates want to see. Therefore, I want to share some less well-known aspects of movies and disability. First, while I’m personally not a fan of horror movies, zombies, or vampires, I couldn’t help but be impressed by what I read about a movie called,
Spring Break Zombie Massacre. Created and starring two teenagers with intellectual disabilities, who met in grade school at a Special Olympics, and funded via Kickstarter, this movie is described as the ultimate teen zombie movie. The pair are heroes with bionic superpowers who are the only ones able to stop the zombies [29].

Quite different are the efforts of transgender, disabled director Dominick Evans, who has over 21,000 followers on Twitter and runs a regular Twitter conversation about film called #FilmDis. This is described as a discussion of “Equality in Film in front of and behind the camera” [14].

Finally, filmmaker and parent, Dan Habib’s 2009 documentary, Including Samuel, featured his son and four other families who experience disabilities:
Before his son Samuel was diagnosed with cerebral palsy, photojournalist Dan Habib rarely thought about the inclusion of people with disabilities.
Now he thinks about inclusion every day. Shot and produced over four years, Habib’s award-winning documentary film, Including Samuel, chronicles the Habib family’s efforts to include Samuel in every facet of their lives. The film honestly portrays his family’s hopes and struggles, as well as the experiences of four other individuals with disabilities and their families. Including Samuel is a highly personal, passionately photographed film that captures the cultural and systemic barriers to inclusion [16].

Literature: There is a lot of literature featuring disability, including my own work. One of my favorite sites these days is called, “Disability in Kidlit”, which is, “is dedicated to discussing the portrayal of disability in middle grade and young adult literature. We publish articles, reviews, interviews, and discussions examining this topic from various angles—and always from the disabled perspective” [9].

Music: In February 2015, in a blog called, “My Top 25 Disability Pride Songs,” I wrote:
I love music, and as someone who came of age as a protester in the late 1960s and early 1970s, I appreciate how music, protest, culture, and change,
connect.... In compiling these songs, I included a variety of genres, cultures, and countries, because musicians with disabilities are creating in all of them and because, with international access, those of us in the U.S have access to, and are influenced by, what is happening all over the world [6].

This seems like a great place to recognize the work of my friend, Leroy Moore, founder of the Krip Hop Nation. While Krip Hop takes its name in part from its revolutionizing of Hip Hop music, it is also self-described as “More than Music.” And in that sense, I want to share Leroy’s article, “New Term Using History Internationally to come up with the Present: AfroKrip:”

In my vision there is a process or steps to get to AfroKrip. AfroKrip at the highest level is a common political stage where the person is comfortable with their identity as a person with a disability and are throwing off the mainstream brainwashing of overcoming or hiding disability to also reach beyond themselves to others for community and discovery of history building on arts and struggles of our African disabled ancestors [24].

As we discuss Disability Culture(s) it is vital to recognize that there is not a monolithic Disability Culture. There are, like with disabilities themselves, dynamic, constantly changing, and newly-discovered disabilities—and cultures, such as Leroy describes above.

While I’m a bit older than Leroy, there are a whole slew of activists in the U.S., who describe themselves as Generation ADAers. One of those young folks is a black woman named Vilissa Thompson, who’s created a stir with blog posts via her website, “Ramp Your Voice!” Vilissa, who I know from the Internet, writes that she will use “Ramp Your Voice!” to:

- spotlight the issues and barriers of people with disabilities, as well as create effective social and political changes to ensure that all people have the ability to succeed and prosper, regardless of their ability, ethnicity, religion, socioeconomic status, educational level, or place of origin [31].

Thompson has been doing this with posts like, “#DisabilityTooWhite: Making the “Good Trouble” in Advocacy,” in which she also created the Twitter hashtag “#DisabilityTooWhite.” She described 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 [30].

This hashtag quickly went viral and the conversation continues. Which given the presence of both Vilissa and Alice is no shock.

I didn’t know, or know of, Alice Wong before moving the Bay Area in 2014, but I quickly learned about her. We have become friends, but it is also fair to say I’m a huge fan of Alice and her work. A year or two ago, when we in the U.S. were thinking of different ways to celebrate the 25th anniversary of the signing of the ADA in 2015, Alice conceived the Disability Visibility Project, which is described as:

- an online community dedicated to recording, amplifying, and sharing disability stories and culture. The DVP is also a community partnership with StoryCorps, a national oral history organization. One individual, Alice Wong, runs the DVP (with the support of several volunteers). Our aim is to create
disabled media that is….intersectional, multi-modal, and cross-platform. Like a virus invading a host organism, stories by disabled people can alter the structure and very DNA of mainstream media. Transformative culture change from the inside/outside/every direction [12].

Alice also has the distinction of being the first person to visit the White House robotically [27].

**Parades and Protests:** When I was a young(ish) advocate in the 1980s, I met a woman from Boston who talked about and implemented a Disability Pride Parade in 1990. Unfortunately, she died young and so did that Parade. But then Sarah Triano, of the “Disability Pride” definition, became a primary force in developing Disability Pride Parades in Chicago in the early 2000s. The first was held in 2004 and has been an annual tradition every since. It has also grown and I had the pleasure of being Grand Marshal in the 2005 Chicago parade and marching a few years later in a Stockholm parade.

Parades and Protests may have similar themes: gathering to celebrate; marching to protest. ADAPT has been around since the early 1980s, first protesting the lack of wheelchair accessible buses and over the years moving to a focus on community integration. Photographer Tom Olin, who has been at many ADAPT protests, is often considered the foremost photographic chronicler of the Disability Rights Movement [11].

In discussing this presentation a question I was asked was how disability culture can be used to create change. I hope that you have seen ways that can happen. But I would also ask of each of you the following questions that may be useful in your everyday lives to use disability culture to create change. For example:

1. How would you create disability culture?
2. Can you facilitate the creation of culture?
3. How would you use examples of disability culture of which you’re already aware to create more disability culture?
4. How would you use Disability Culture to create change?

Three Taiwanese women combined protest and culture. Sandie Yi and Sleeve Yu protested in front of the Taiwan National Theatre and Concert Hall (NTCH). This building is being renovated after 30 years and a banner on the building reads “See You Next Spring (NTCH is scheduled to reopen in Spring 2017). The building is closed for renovation after 30 years of operation, but NTCH ignored the fact that they need to provide 12 wheelchair accessible seats by law (they had 5 and were going to add only one more). NTCH argued that adding wheelchair seats would affect the acoustic quality, create barriers to emergency evacuation and cause loss of revenues. Sandie provided real case studies and used examples from The Kennedy Center in the U.S. to counter some of the arguments presented by NTCH. NTCH was asked to respond to the demands of adding wheelchair seats within one month. After the meeting, Yi and Yu and a few disabled activists began critiquing NTCH via social media and attracted supporters and fellow-activists to join the fight. While waiting for NTCH to respond, Sandie and Sleeve then initiated an online photo event, asking people to share their experiences with attending inaccessible arts and culture events. They also asked people to name their hopes and dreams for a better and accessible arts and culture experience. They invited people to write their own words on paper and photograph themselves in front of the arts and culture venues (Personal Communication, August 2, 2016).

Grace Chang protested in front of the National Museum and Opera House about a lack of more seats for those using wheelchairs. Her protest poster read “Equal Rights for
Participating Culture. Give us more wheelchair seats.” According to the Accessibility Act to Public Buildings the building lacks a required 19 seats, but there have been no fines or penalties. (Personal Communication, July 31, 2016).

What ways might you use Disability Culture to celebrate, protest, and/or create change?

Music Videos: Another example of Disability Culture is one of my favorite videos, Mobility International’s “Loud, Proud and Passionate!” which shows women from all over the world creating change. A line from the video perhaps may be a Manifesto for how Disability Culture can be used for change: “Making our dreams come true, knocking down the barriers; changing the world, there’s nothing we can’t do” (Thank you and let’s all move forward Promoting Disability Pride!

References: