

The Emergent Art/Disability Discourse

by John R. Killacky

Nine years ago, doctors found a tumor inside my spinal cord, at C3. Because it was inside the cord, surgery was the only solution. I was told I would be in the hospital for three days and have a sore neck for a month. I woke up from surgery, paralyzed from the neck down

I spent six weeks at the Sister Kenny Institute learning to navigate my mis-circuited body and continue to do intensive rehab. Most days I meander through the world with my cane. On family outings, I sometimes use a wheelchair.

Prior to surgery, I had been running Walker Art Center's performing arts program. The mission was to present contemporary and avant-garde artists. Looking back, there were many wonderful memories of presenting artists with disabilities, but I was not always the most sensitive.

One January I invited AXIS Dance Company, a mixed ability company from Oakland, to perform in the annual "Out There" series. Artistic director Judy Smith who uses an electric wheelchair, wondered if this was the optimal time for her company to perform in Minneapolis, given that it was usually well below zero and under several feet of snow.

I insisted her company would be best seen within my aesthetic framework of "Out There." AXIS performed beautifully, but not without complications. As Judy wheeled the one block from the hotel to the theater, it was so cold her tires froze and blew out. It was not the most auspicious beginning of a dear friendship.

After surgery, I relocated to San Francisco to run Yerba Buena Center for the Arts. For obvious reasons I wanted to reach out to the disabled community. I met with organizers from the World Institute on Disability and invited them to have their annual gala at the center.

The event sold well; we had a pretty full house in the 750-seat theater. Fire alarms unexpectedly went off and we had to evacuate the theater. My house staff was ill prepared. This is not something you want to happen in your theaters filled with disability advocates. Luckily it was false alarm.

As I look at our field today, I am frustrated as many of you are. Even though reasonable accommodations are federally mandated, art facilities and programs remain inaccessible. I sit on a lot of grant panels and am impatient when most organizations define accessibility primarily through architectural accommodations. What happened to programs?

Many of you are leading the charge to move beyond compliance and make processes and programs accessible. You understand accessibility is much more than ramps, seating, listening devices, large print programs, and sign language interpretation.

Exhibitions, lectures, films, interactive computer displays, plays and concerts examine disability, as well as materials about programs – catalogues, labeling, scripts, libretti, brochures, maps, and publicity have become more accessible. We should celebrate the progress that has been made. Kudos to The Kennedy Center for gathering us together to share best practices and to learn how to overcome obstacles.

Interestingly enough, as more artists with disabilities are invited to perform and exhibit work, we are faced with making backstage areas more accessible. This may be the next frontier of work within our institutions.

Last year I was doing an on-stage conversation with dancer Bonnie Lewkowicz at The Oakland Museum. Bonnie uses a wheelchair so we decided to ride an offstage lift to get onto the stage. Well it jammed and we were stuck for 20 minutes while the staff frantically looked for a key and for someone who knew how to use it. When we finally made it to the stage, it was some entrance.

Fifteen years ago, ADA legislation defined access as a civil right and the law. Because of your work, organizations are now beginning to understand accessibility as an organizational asset...to be thoroughly inclusive not because they have to, but because it is the right thing to do.

There are 54 million disabled adults and children in this country, accounting for 20% of the population. Our aggregate income tops \$1 trillion. This includes \$220 billion in discretionary income.

Let's also look at demographic trends. There are 36 million people age 65 and over in this country, accounting for just over 12% of the total population. Seventy seven million Baby Boomers will start turning 65 in 2011. By 2030 the older population will grow to 71.5 million, representing 20% of the U. S. population.

Add together the increasing number of seniors and people with disabilities, and factor into the equation their spending power plus the importance of ticket sales and fundraising. The sum is clear: accessibility equals smart business.

All change happens from the fringes. Think about political, social, or aesthetic movements in our lifetime. Civil rights, woman's rights, gay and lesbian rights, and AIDS activism gave rise to new cultural forms. The avant-garde continues to challenge norms, expectations, definitions, and perceptions of art for future generations.

Disability activism has had a huge impact. Accommodations originally designed to serve people with disabilities have enormously improved the quality of programs for the broader public, even if they may not be aware of the origin.

Skateboarders and parents with strollers relish ramps and curb cuts. Closed captioning allows us to watch the news while exercising on treadmills and stationary bicycles.

Seniors gobble up assistive listening devices at theaters. Electronic devices to monitor elder health and well being abound. Children understand dimensionality better with tactile models of sculpture.

Power doors make it easier leaving the grocery store. Screen reading software and computerized speech synthesizers make our computers even friendlier. Penguin and Simon and Schuster are introducing a new bigger format to allow larger type and more space between the lines to make books more appealing to aging readers.

Earlier, the conference discussed universal design's intention to make products, communications, and the built environment usable by as many people as possible. Given the demographics, this is not only the right thing to do, but also prudent. A recent article in *The New York Times* estimated that 25% of all American households care for a frail friend or relative. Universal design concepts make it easier for all of us.

While arts organizations have made progress with accommodations, artists also have to embrace accessibility as an asset. Signed performances and assisted listening devices are commonplace in theaters, yet it is still a radical notion to have audio description available for all art forms. Many visual artists, choreographers, and composers are opposed to this kind of interpretation, fearing it will take something away from their work.

However, these very same artists have been grappling with how to reach new and broader audiences. How many of us would appreciate an audio described tour of contemporary art that could help us understand different ways of looking at challenging work? This is only a notch harder than the celebrity-voiced tours many museums offer for their blockbuster shows already.

At Walker Art Center, we mounted a Jasper Johns exhibition. For the opening celebration, I invited John Cage to read a piece he had created by randomly rearranging writings by Jasper. We got a request for ASL interpretation for the event. At first, John was opposed to having someone sign the reading, but once it started he became utterly entranced. The only problem was he often stopped speaking so that he could watch the signer, who of course stopped the signing once John stopped speaking.

With a faculty exhibition I curated for the San Francisco Art Institute, I was discussing the concept on the phone with one of the artists I had not yet met. She insisted her photographs were best seen when hung at her eye level. I reminded her of the ADA guidelines, and she retorted, "Those people don't come anyway." I could not wait to meet her in person.

In a show at Yerba Buena Center, a gallery director threatened to pull an artist's ceramics from an exhibition because the shelf was not at his eye level. I told her I was more concerned with the public's eye level, and she was welcome to withdraw the work.

I too grappled with accessibility as a filmmaker. I was startled the first time one of my works was close captioned; thereby disrupting the visual frame I had so carefully

constructed. However, I am reminded of a speech Marcel Duchamp gave in Houston in 1957:

“All in all, the creative act is not performed by the artist alone; the spectator brings the work in contact with the external world by deciphering and interpreting its inner qualification and thus adds his contribution to the creative act.”

So art is enlivened and completed through its audience and that audience must include all of us in this room. It is our legal, civic, and moral right.

I would like to now turn my attention to the artists in the audience. A few years ago, I attended a disability arts conference in Los Angeles. I was eager to connect with other artists who had traveled from all over the United States and England. Actors railed against the inequity of being brought on location to teach “real” actors to mimic their actions. Artists who use wheelchairs wondered if they could only play their disability.

Perhaps it was because we were in L.A, but I was struck at how many artists were using the commercial entertainment industry as a barometer of success and validation. Mainstream culture has never been of much interest to me and Hollywood does not represent anybody well.

A recent study by Olivia Raynor commissioned by the Screen Actors Guild showed that less than 2% of the characters on television display a disability and less than .05% had speaking roles. Only a third of guild members with disabilities reported working in a theatrical or television production in 2003, and 60% said they never asked for accommodations because they thought that would make employers reluctant to hire them.

People shared performance work at this conference and not surprisingly, it was wildly uneven. One quadriplegic comic shared her latest sketch. She was not very good, but no one gave her feedback on how to make her routine stronger. It seemed indelicate to tell a quadriplegic that she was not funny, but if you tell jokes, you have to land the punch lines and she had not. By not engaging in a conversation about her work, we did not take her and her work seriously.

I came back from the conference newly fortified to continue creating more personal images, as well as finding ways to empower and make opportunities for training, skill building, and critical discourse. Society underestimates our creative potential, often reading our work through medicalized and infantilized lenses.

If we are going to stop being objectified, we need to control our own images, take ourselves more seriously as artists, and challenge and support each other to make better work. The remarkable thing is NOT that people with disabilities are on stage or in galleries, we also must be judged on aesthetic terms as to how we draw, act, dance, play music, and make films. Otherwise artists with disabilities remain a Carney freak sideshow.

Judy Smith, talks about how the dance world and mainstream press did not take AXIS seriously in its first ten years. Oftentimes they received what she calls “sympathy reviews” wherein critics would write about how inspirational the dancing crips were.

Judy also realized that she needed to up the artistic ante for herself and her dancers. She therefore invited in accomplished choreographers like Bill T. Jones, Ann Carlson, Joe Goode, and Victoria Marks to create works. What had been a company of disabled dancers became a critically renowned ensemble of dancers with disabilities.

This is much more than semantics. The transformation of this company in the last few years has been remarkable, including appearances at The Kennedy Center with Baryshnikov, a six-week tour in New England, and acclaimed performances in New York.

Judy Smith from AXIS is one of six artists I featured in “Crip Shots,” a video I made four years ago. It has been shown in film festivals in 25 cities worldwide and at disability film festivals in Toronto, Moscow, Adelaide, Melbourne, Bombay, Calgary, Munich, Winnipeg, and Berkeley. A number of universities and libraries acquired the video for their collections and it aired on Free Speech TV.

I am currently shooting my fifth video emanating from my experience of disability, focusing on three households in which one person is disabled. The couples candidly discuss the physical, emotional, social, relational, and psychological ramifications of living with disability.

In addition to making videos, I had a fascinating three-year journey publishing a book of writings by gay men with disabilities. Other anthologies were my inspiration: Kenny Fries’ “Staring Back: The Disability Experience From The Inside Out,” Raymond Luczak’s “Eyes of Desire: A Deaf Gay and Lesbian Reader,” and Victoria Brownworth’s and Susan Raffo’s “Restricted Access: Lesbians on Disability.”

I joined forces with Bob Guter, editor of “bent voices,” an Internet site for disabled gay men, to compile the collection. Putting the book together was the fun part. Publishing was more daunting. Thirty presses turned us down. Gay publishers told us without buff men or lipstick lesbians, there was no market for the book. Disability presses told us their focus was on the positive side of disability. Our book was not filled with smiling heroic crips, but real people grappling with catastrophic and sometimes dark issues.

Eventually Haworth Press agreed to publish “Queer Crips: Disabled Gay Men and Their Stories.” Even with its small niche nature, it has relevance and found a place in the world. It won a national Lambda Literary Award and is included in Gay and Disability Studies curriculum in Illinois and California. Being the good author I am, I did bring a few copies with me.

Philip Patson, who runs the Giant Leap International Disability Arts Festival in Auckland New Zealand states:

“Throughout the 20th century the development of art, performance, and culture in marginalized communities has reflected an increase in those groups self-determination. We have seen this exemplified by the emergence of woman’s literature, indigenous music, and queer arts, for example. For disabled people, the process is the same. We are reaching a breakthrough point in the development of disability arts and culture worldwide.”

VSA Arts has been a pioneer in this. In its 30-year history, artists with developmental, physical, and mental disabilities have participated in arts activities and developed skills. For many of us, an art practice became a method of communication, expression, and self-realization. Work dismissed as devoid of aesthetic qualities is now being taken seriously as art rather than a curiosity.

Visual artists who are disabled are now featured in outsider and folk art fairs, exhibited in galleries and museums, and are in private collections in the United States, Japan, and Europe. In addition to AXIS, there are a number of mixed ability dance companies: Dancing Wheels in Cleveland, DanceAbility in Portland, Dance Detour in Chicago, Full Radius in Atlanta, Infinity Dance Theater in New York, Inflight Dance Company in San Antonio, Light Motion in Seattle, and John Beauregard in Miami, to name a few.

An American Sign Language adaptation of “Big River” played on Broadway last season and had a successful national tour. “Murderball,” a documentary about wheelchair rugby, was a hit at Sundance and was one of the summer’s surprises, earning \$1.5 million at the box office. It is a sign of progress when people with disabilities can play themselves and also be jerks, rather than having Daniel Day Lewis, Tom Cruise, and Hilary Swank playing transcendent crips vying for Oscars.

Yet with all of our success, there is much work to do. We are only in the second generation of the disability rights movement. At least we do not have to throw ourselves out of our wheelchairs and crawl up the steps of state and federal buildings to be heard.

The truth is, fifteen years after ADA, we are still discovering what our work is. Access is not just about architecture; it has to be at the heart of every organization. Your efforts are making a difference, for all of us now and in the future.

As for the artists in the room, our challenges in life give us unique perspectives much needed in the world. After all, humanity is defined through difference, not sameness. Your talents illuminate and give insight into realities many have not experienced. We have much to offer; god speed in your efforts.

John R. Killacky is program officer for Arts and Culture at The San Francisco Foundation. These remarks were excerpted from a Keynote Address at the Kennedy Center’s Leadership Exchange in Arts and Disability Training and Conference in Scottsdale Arizona, October 1, 2005.