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CARE WORK

DREAMING DISABILITY JUSTICE

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PREFIGURATIVE POLITICS AND RADICALLY ACCESSIBLE PERFORMANCE SPACES

MAKING THE WORLD TO COME

> *If, as the African revolutionary leader Amílcar Cabral described it, culture is the "collective personality of a people," then the arts are its collective dreamlife. In the absence of coercive control, the arts, like dreams, are naturally drawn to the deepest hopes, fears, and truths that are suppressed in daily life ... art becomes conscious dream-telling, responsible creation with the potential to affect the life of our people.*
> *—Ricardo Levins Morales*

Prefigurative politics is a fancy term for the idea of imagining and building the world we want to see now. It's waking up and acting as if the revolution has happened. It's, for example, building a sliding scale community acupuncture clinic that is affordable and centers disabled and working-class/poor and Black, Indigenous, and people of color instead of writing reports about how the medical-industrial complex is fucked up. (Though that can be important too.) I think of it as akin to the Allied Media Conference principles of "We spend more time building than attacking" and "We focus on our power, not our powerlessness."

The higher education programs where I studied writing and performance taught basically zero about creating accessibility in making performance art, theater, and spoken word. The focus was almost always on creating the work of Art, in a vacuum. Almost no attention was paid to the audience, the performance space, the container, and the community for the art as being as important as the art itself, and not separable from the art. Practical skills—from how to make a flyer or a budget to how to do successful ASL and make a fragrance-free space or a performance whose pace was accessible to non–hyper-able-bodied performers—were neglected in those ivory towers. I think that if anyone had asked about how to create accessible spaces, for performers or attendees, they would have been, gently or not so gently, dissed. That stuff, that's about community-based art, or art therapy—not real, professional, capital A art. As a performer and curator/producer, I believe that how you do it and who is there to see it is are as important as what is on the stage. My favorite performance spaces are spaces that become temporary, two-hour communities that are autonomous zones that feel like freedom. Being in them, we can smell and taste and feel things we have always wanted but rarely witnessed—both in what we see on stage and how we interact and participate as an audience that serves as a community of witnesses. Having an accessible space for performers and attendees and workers, where disability is not marginalized, tokenized, or simply absent, is very different from having a performance space that is full of mostly able-bodied, young, non-parenting people who can afford to spend the money to attend and/or to get there in the first place.

As oppressed people, we don't control a lot of things. But one thing we can sometimes control is the stage. The stage can be prefigurative politics.

I often tell a story about Patty Berne, the cofounder and Haitian Japanese femme powerchair-using disabled badass artist and organizer of Sins Invalid. I once asked her why she had chosen to use performance art as her primary way to advance disability justice. Why not just do a workshop? She paused and said, "You know, I could do workshops until I was blue in the face, trying to convince white disabled people or able-bodied people of color to care about us. And I've done that. Or I could make a three-minute piece of performance art that shows them the inside of their dreams and nightmares and fucks their shit up. I chose that route."

Disability, access, and accessibility are rarely thought about in performance. Access is a guilt-ridden afterthought, when it's thought of at all, and it's usually only thought of when disabled people ask about accessibility. This request is usually responded to with guilt, with defensiveness, with surprise, with bad or nonexistent or last-minute scrambles for access, or with simply with abled tears. Because, as Qwo-Li Driskill says, one way ableism works is that disabled people "are not even present within the imaginations of a supposedly radical future."[41]

Further, in ableist, mainstream performance spaces, access is mostly only ever considered—maybe—when audience members are concerned. In my experience, most theater managers and staff never imagine that performers, directors, light and sound techs, stage managers, and volunteers could be disabled. Writing this, I can remember clearly the pause on the other end of the phone when I asked my contact at a performance space whether the stage was accessible, after he'd said, "Oh yeah, there's a ramp at the door" three times, and I'd said, "Yes, but is there a ramp for the *stage?*" He couldn't imagine that one of the performers was a wheelchair user. When he finally got it, he said without hesitation, "Well, I guess she'll just have to perform on the floor," without thinking for a second about the second-class place implied by that state—able-bodied and walkie crips get the stage; you get the floor.

This fucks everybody over, because more access is more access for everyone! Don't get me started about the theater manager who said,

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[41] Qwo-Li Driskill, with Aurora Levins Morales and Leah Lakshmi Piepzna-Samarasinha, "Sweet Dark Places: Letters to Gloria Anzaldúa on Disability, Creativity, and the Coatlicue State," in *El Mundo Zurdo 2: Selected Works from the Society of the Study of Gloria Anzaldúa*, edited by Sonia Saldivar Hull, Norma Alarcon, and Rita E. Urquijo-Ruiz (San Francisco: Aunt Lute, 2012) 75–98.

"Oh yeah, it's accessible" to me on the phone, where we showed up on opening night to find a gorgeous ramp from the green room to the stage, and rejoiced. Two years later, when we showed up again, the ramp was gone. What happened? "Oh, we built it for you because we knew you had someone in a wheelchair, but after your show was over, we tore it down," a staff member explained helpfully—as if this made sense. My friend, Black, wheelchair-using, queer, femme dancer and writer Neve Mazique-Bianco, looked at me levelly when I broke the news and said, "Leah, we just have to remember that the abled will destroy access at all costs." The irony was that nice wide ramp would've helped everyone—people in chairs, people using canes, and normals who just needed to haul a lot of props onstage the way, you know, you usually have to in theater. But there you have it. Oppression isn't helpful or logical.

We are not supposed to be healers, because we are obviously "unhealed" and broken, according to the ablest imagination. And we are not supposed to be performers, except in a "clap for the brave cripples, but don't expect them to be a) good b) have some shocking shit to say that you didn't expect" kind of way. The charity model infects even how crip art can be thought of, or if it can be thought of at all.

Which brings me, though, to the joyous work of setting up performances and what happens when making access happen is not an afterthought to producing performance but a central part of visioning and creating that performance, from the beginning.

Perhaps you've heard the idea that the audience makes the performance. As a performer of color, I know that performing to an all QTBIPOC audience is very different from performing to one that is majority white (or to one where white people have grabbed all the seats right at the front).

The audience at a Sins show is as important as the show. Is part of the show. Because it is a portrait of cross-disabled, deeply accessible space that is also Black, brown, and economically accessible.

When I went to a Sins show for the first time and ran smack into crip culture—a line of chair and scooter users right at the front; a line of Deaf, Hard of Hearing, and signing folks at the front right in front of the 'terps; short folks; cane users; folks with PCAs; folks in pain, dressed up, dressed all in white, popping pills, flirting, spraying active enzymes under their tongues to withstand chemicals they were surrounded by, sitting by audio describers; Black, brown, and white; no one turned away for lack of funds—it fucked me up in the best way and changed my life. This was the audience. I was a part of the audience. A brown, sick part. We were not translating and we were not trying to pass as abled or fighting to just get in the door or to see five seconds of ourselves onstage, and the world was the world to be. And we were not "Sorry, the space is inaccessible, but you can watch it on the livestream!" (Note: I am all in favor of livestreaming as being a way to make performance accessible to folks who are unable to make it to the show because of money, sickness, fatigue, etc., but livestreaming is not an okay fix for an inaccessible venue—sick, disabled, Deaf, and crazy folks would like to be part of the community gathering to witness performance too.) We were not an afterthought. Able-bodied people could come, but they weren't doing us any favors.

Over the next few years, as I grew in disability consciousness and identity, and took part in hanging out, talking, thinking, and building DJ culture with other sick and disabled folks, I started thinking a lot more, and trying to put into practice, accessible booking and producing. I learned a lot from others doing this work.

It took a long time before I realized that the work I was automatically doing as a disabled producer—buying the fragrance-free soap, booking ASL and doing Deaf promo and making sure that everyone got their scripts in to the 'terps two weeks in advance, taping off lanes thirty-six inches wide, figuring out where interpreters, Deaf, and HOH folks could sit near each other and still have clear sight lines, doing preshow education about fragrance-free, recruiting childcare workers, calling venues multiple times to punch through their "Oh yeah, it's accessible" to find out what that really meant, cocreating an accessible venues Google doc—was both a specific skill set of accessible performance skills and its own job that no one should be doing *and* directing, performing, etc. And that it was an invisibilized labor because it is feminized, disabled cultural labor. And it is never taught in a theatrical or performance MFA. And mostly, when it happens, it happens because sick and disabled and Deaf and crazy folks make it happen, because we are the ones who a) care and b) have the sick/disabled/crazy/Deaf science and skills to make it happen.

Five years after I attended that first Sins show, when I was working on booking the Mangos with Chili Toronto show, I listened to myself as I explained that the culture in Toronto had shifted—not at all fully, and not automatically, but through years and decades of cross-disability and Deaf cultural activism in Toronto, and it was no longer just acceptable business as usual all the time to have queer performance in inaccessible spaces. People who did could expect resistance and a community raising our voices in anger. (I say this with hesitation, knowing that there are still so many inaccessible spaces, and that this is an ongoing work in progress—but also wanting to mark that accessibility awareness in Toronto QTBIPOC and activist performance spaces does feel broader than in many cities that I have visited. And that that happened through the labor of many, many disabled, chronically ill, crazy, and Deaf folks and allies, and deserves to be celebrated.)

And I was rewarded. At the show, there was a line of signing folks right up front, parents who were able to watch burlesque because there was childcare on-site, chair users with nice wide rows and clear beginning and end times marked on the invite so Wheel-Trans bookings could happen, frag-free seating, folks who left halfway through because they got too tired, youth, and elders.

That crowd was the show.

And more than that: that crowd was the movement and community I want to live in and make art for and with. It was the opposite of an inaccessible performance space filled with able-bodied, non-parenting, young queers. For three hours, it was a cross-disability, parenting, and mixed-class community where I felt like all my parts could come home. I didn't feel like I was pushing myself to be in a space that was inaccessible, and where the fact of disabled people wasn't even present. I wasn't at home, staying away from an inaccessible and alienating space, worried that I would fade from people's memory or become a "Whatever happened to her?" because I had just stopped going to inaccessible spaces. Where I was not isolated from other disabled, Deaf, chronically ill, and/or Crazy folks because of the walls ableism enacts to separate us from each other and forcibly isolate us.

That show and crowd—it was the world to come.