

Notes for Sick Time, Sleepy Time, Crip Time-a field guide

by Taraneh Fazeli

This essay was written by Fazeli in the Fall of 2020 as part of Banff Centre's Curatorial Futures program, shortly after the wave of uprisings against Anti-Black racism and amidst a US presidential election, COVID shutdowns, and other important events highlighted in the text. Since she felt the questions of the moment that most needed grappling with could not be neatly consolidated or answered within any one essay, Fazeli undertook a series of writing exercises of which this essay is one of to identify the guiding concerns of a field guide she was beginning to edit. The field guide emerges from her curatorial project *Sick Time, Sleepy Time, Crip Time: Against Capitalism's Temporal Bullying*, a series of art exhibitions, programs, and community projects with associated transformative institutional work that occurred from 2016-20. At the project's core was the pairing of disabled, Sick, Mad, immigrant, QTBIPOC artists with community groups such as local disability groups, recently incarcerated women, young single mothers, refugees or asylum seekers, activists experiencing burn-out, and others. It brought investigations on the politics and practices of disability, health, and care into contemporary art's mainstream, while challenging host and partner organization's approaches to care.

In [*Sick Time, Sleepy Time, Crip Time-a field guide*](#) (publisher forthcoming), a set of "tools" are framed by "case studies" from the project and its ongoing network that detail complexity of implementation. The "tools" include adaptable guides towards better care, such as accessibility guides + riders, somatic facilitation scores, conflict resolution guides, community benefit agreements, and decolonial and anti-racist practices. In the "case studies" artists, care-workers, care collectives, and organizers rethink received practices and definitions by using the material of care and lived experiences with disability and debility as creative material (crip time, access, inter/dependency). They examine how they've used creative spaces to express love for disabled lives, resist ableism's intersection with

racism and colonialism, and build collective wellbeing and health autonomy. Compared to other disability tool kits, the field guide offers practices rooted in the complexity of making accessible worlds with different sets of lived experiences and ways of being at the center that may not necessarily engage in dominant Western accessibility discourses. Its access-centered approach focuses on creating access where one is with the resources and needs there, while also sharing tactics to demand institutions transform and redistribute resources.

Sanctity of life

On the left of the split screen is a woman with hazelnut-colored skin, semi-glossy lips, and shoulder-length wavy brown hair. She wears a black blazer with a shimmery black shirt underneath. A small microphone is affixed to her lapel. She is adorned with nickel-sized round pearl earrings, a pearl necklace, and a rectangular US flag pin slightly smaller than a US postage stamp. Behind her is an ocean-blue wall with indecipherable cursive English writing running across it. On the right appears a light-pink—skinned man with short white hair, thin lips, and light-brown eyes. He wears a dark-blue suit jacket, crisp white shirt, and shiny red necktie. He appears to be in front of the same wall and is also wearing a microphone and flag pin. His pin's wavy shape makes the flag appear to be blowing in the wind. He looks with narrowed eyes towards the left side of the screen while the woman looks back, with her eyebrows raised. She says, "Excuse me, I'm speaking."

This image description is of a video that live streamed across the globe the day I began writing this essay in October 2020. A pan out reveals the text behind them to be from the US constitution. The room's spatial layout—in which two transparent glass dividers resembling privacy screens separates the two figures—mirrors the split video screen and provides a metaphor for the country's increasing polarization. This debate took place between US Vice Presidential candidates Kamala Harris and Mike Pence on the evening of October 7, 2020 in front of a socially-distanced, masked audience. In combining a limited indoor event with live streaming, the

debate resembles many gatherings during viral times. Tellingly, there was no ASL interpreter present or live captioning.¹ Their absence was one indicator of who has access to this democratic public sphere and whose lives matter within the bio-political frameworks emerging from it.

Electoral debates typically involve a rhetorical dance in which the moderator's questions are twisted to fit the candidate's strategic narratives and evade polarized issues that might cost them votes. The debate occurred several months after state-organized celebrations for the thirtieth anniversary of the Americans with Disability Act (ADA), during overlapping pandemics of COVID-19, racism, ableism, and fascism. Despite progress on disability rights, the unwillingness to support disabled people or engage with the topic of disability reveals prevailing discomfort across party lines.² Reflecting the medical histories of the two septuagenarian presidential candidates and standing President Donald J. Trump's current diagnosis of COVID-19, the initial question posed is whether the Vice-Presidential candidates discussed contingency plans in case of presidential disability. Neither respond, so there is a follow-up on the US-American people's right to transparency around the president's health. The moderator goes on to inquire whether Harris and Pence believe their home states should permit abortion if federal legislation protecting access were to be overturned. The context is the unprecedented attempt unfolding by Republicans to confirm a new justice to the Supreme Court during an election following the death of Justice Ruth Bader Ginsburg, a liberal advocate for gender equity. The conservative nominee, Amy Coney Barrett, could possibly be the decisive vote to overturn the Roe versus Wade ruling, which protects abortion rights, and the Affordable Care Act, which removed health insurers' abilities to withhold coverage due to a person's pre-existing medical conditions.³ Neither candidate responds directly, instead invoking personal beliefs: Harris advocates for the right to choose before arguing for universal healthcare; Pence upholds "the sanctity of life." This anti-abortion euphemism is used interchangeably with "right to life" by religious conservatives; both phrases indicate privileging the rights of an unborn fetus over the rights of the pregnant person carrying the fetus.

These exchanges raise necropolitical questions about whose lives matter within human rights-based frameworks, and how elected officials using such expressions will act to uphold this “sanctity.” The Universal Declaration of Human Rights places the right to life alongside the right to freedom from torture and inhuman degradation.⁴ A question regarding the role of targeted debilitation and disablement of racialized, specifically Black, populations in state securitization processes in the (un)justice system follows in the debate, although with less-pointed language. Harris speaks to the racial bias of the police and commits to banning police chokeholds and carotid holds if elected.⁵ Unlike Harris, Pence refuses to recognize any racial bias.

Harris, a child of immigrants from India and Jamaica, has broken racial and gender (although not class) barriers in her rise to power as a mixed-race Black woman. While representation matters and can help create realities, identity is complex and does not in itself predict political commitments. Anti-racist movements frequently highlight how Harris in her early career as local prosecutor once referred to herself as “top cop.” The liberal progressive platform organized around unity that she and Joseph Biden campaign on now promises reform to police and prisons. Compared to Trump and Pence’s platform, it promises to lead to some positive impact on the lives of Black people who are disproportionately harmed by carceral systems. But many ask, how far can these institutions be reformed?^[SEP]

Progressive liberal fantasies of unity

As I return to writing this in November 2020, concerns of a coup mount as Biden wins the popular vote and electoral college, and President Trump refuses to concede while making unfounded accusations of voter fraud. Amidst world-wide protests against anti-Black racism, white-led organizations have been performing the rhetorical stance of inclusion but when tested, they aren’t so willing to let go of their comfort or power.

I receive an email from the director of an arts organization several years after I was curator-in-residence. He is seeking permission to cite, as a

keystone of the organization's equity work, the access initiative I implemented there as part of *Sick Time, Sleepy Time, Crip Time*, my iterative itinerant exhibition on the politics of health, disability, and care. His draft version of the many "I want to do better letters" circulating highlights the access note I created for the exhibition alongside a land recognition, which was created by another curator-in-residence in dialogue with local Indigenous communities. Beyond that, the only tangible efforts the letter mentions are a year-long staff and board anti-oppression training and the related formation of two caucuses, one for people of color and the other white. It does not give details on the racial makeup of the staff, funding sources, leadership processes, or specific actions it plans to take besides consulting "leading voices in organizational transformation."

In my opinion, it is telling that two practices implemented by guest curators—the Indigenous land recognition and accessibility note—are used to signal meaningful reparation, action, or care. Steps like these are only the start for art institutions to open up access to historically excluded communities; this takes ongoing exchange and dialogue about what structures of support are needed. Citing statements without executing the associated work is a prime example of how, when the hierarchies and methods in an organization's schema of care conflict with those of the freelance curators who work for them, attempts at transformation will, at best, occur as a suspension of norms that last only long as the curator's programming or, at worst, not at all.

During my show I asked the organization to make basic accessibility improvements for disabled artists, staff, and visitors—for example, to provide ASL or other language translation, and touch and descriptive tours. I allocated funds for support from my exhibition's budgets and did the associated preparatory work myself, like sourcing local interpreters to contract upon request. Since the organization would not commit to an ongoing accessibility plan until new curatorial leadership arrived, I agreed to hang a provisional access note and advise later how this could be expanded. I reached out several times after I left to offer my uncompensated support with no response. The current lack of image

descriptions or auto-generated captions for online events demonstrates the organization is not implementing basic accessibility practices.

The director's "ask" presents a double-bind—if I refuse, he says attribution will be removed and the work still cited, implying it is the organization's own. The request to endorse this symbolic solidarity perpetuates a longstanding cycle of abuse of Black and other women of color working at the mostly white organization. While stifling our efforts to make meaningful transformations, the organization continues to publicly lay claim to our work. Recently, it offered its social media over to previous Black resident artists to share their art, reproducing a similar tokenizing theft.

Relatedly, the director glossed over his controversial hiring of a musician to manage a new residency program in 2018. The white male musician used a racist anti-Black slur to critique the racist voice of America by embodying it, causing local backlash. Whatever one might think of the artistic gesture, his appointment spoke volumes about who the organization cares for. Subsequently, I refused to produce an exhibition I curated on white benevolence and the limits of empathy unless they agreed to a concrete racial equity plan. After I had finished installation on the understanding the plan we were negotiating would be finalized, the director reneged on publicly committing to this and edited its mention from the show's curatorial statement.

The organization failed, then and now, to connect accessibility and racial equity. Accessibility seeks to remedy ableism, which requires dismantling structures of white supremacy. Community lawyer Talila A. Lewis defines ableism as "a system that places values on people's bodies and minds based on societally constructed ideas of normalcy, intelligence, excellence, and productivity. These constructed ideas are deeply rooted in anti-Blackness, eugenics, colonialism, and capitalism."⁶ Ableism can't be solved by reformist practices of "inclusion" or "diversity," which only seek to expand the current formulation of the institution. In hindsight, I realize the limitations of my accessibility initiative—it was unable to fundamentally

change the organization's practices, and has now been co-opted as part of its language of reform.

A council of mutants organize^[L]_[SEP]

On election night—recognizing a win by Democratic presidential candidate Biden would simply be harm reduction—rather than hope and watch for the map of US states to turn blue, I attended a hip-hop album release party for [*The Mutation Mixtape*](#). Creator Will See (the stage name of Owólabi Aboyade) is a poet, emcee, and grassroots organizer. He eschews the designation of Black in favor of New Afrikan due the political framework it offers.⁷ We first met when I invited him to record a disability justice anthem for the version of *Sick Time, Sleepy Time, Crip Time in Waawiiatanong/Detroit*.

Within that track, See's lyrics address how his ancestors passed on chronic illnesses after being forcibly brought to the US, lynched, and made to endlessly labor in cotton fields filled with pesticides. He often speaks on the complexity of embracing a disabled identity for himself and others in his communities.⁸ This difficulty can be understood through Jasbir Puar's articulation of how certain racialized populations are pre-ordained for injury and targeted maiming, while disability identity is simultaneously seen as a site of creative embodiment and resistance: "the global north holds the key to the liberalization of disability while the global south bears the brunt of its weaponization."⁹ Since the 1960s, frameworks for understanding disability and chronic illness in the US have been shifting: from the single-issue approach of disability rights (largely dominated by white men with physical disabilities); to the intersectional, multi-systemic approach of disability justice, which addresses economic, cultural, and social exclusion based on physical or cognitive difference (largely led by LGBTQIA+ and BIPOC people); to the movement toward healing justice, which embraces non-Western traditional medicines in response to trauma produced by colonialism, racial capitalism, militarism, and imperialism.

The representational worldbuilding in See's creative work links to the infrastructural worldbuilding he does via community organizing and mutual aid. As a self-proclaimed "Detroit Diplomat," he endeavors to link his communities to global solidarity struggles. After Detroit's wealth was decimated by deindustrialization and the collapse of the domestic auto industry, art has played a complicated role in the rebuilding of the Motor City. The city's population is nearly eighty percent Black and Dearborn, a city in the metropolitan area, has the highest percentage of Arab Americans in the US. Consequently, the local culture is rooted in Black liberation, Indigenous, immigration, and labor struggles. Yet resources are directed not to Black and brown communities but to downtown, which has been rebuilt largely through incentives given to several white developers. In the absence of economic systems that provide for them, self-determined diasporic and colonized communities increasingly invest less energy in the critique that dominates much of the coastal art ecosystems and focus on building their own infrastructures instead. For example, See organized a decolonization event around Oya, an Orisha spirit tied to wind, near the site of an incinerator he and many other environmental justice organizers fought for years to successfully shut down. This was motivated by the strategies of maroon communities that, in See's words, did not protest against slave owners but instead liberated themselves by cooperating with the land to get what they needed then going back to free others.

Intentionally coinciding with the election to highlight that we need not participate in the limited paradigms set up for us, *The Mutation Mixtape's* release party was a rallying call "for the mutants, the monsters, the forces of nature to awaken and to announce our intentions to smash normality."¹⁰ In See's verses a narrative unfolds about a coalition of mutants, or those whose body-minds do not conform to white-supremacist conceptions of capacity and are thus deemed defective or expendable. Being mutant is not a superpower nor an identity, it is a state of being. To mutate is a process wherein wisdom generated by surviving oppressions is collectively harnessed and combined with ancestral ways of being that precede colonization or forced assimilation, thereby modeling other ways of being. *The Mutation Mixtape* offers one example of creativity's potential to re-

world by generating intersectional and co-constituted assemblages of decolonial solidarity using storytelling, affect, aesthetics, and sensation so that different ways of knowing and being can cohere. In a field guide for *Sick Time, Sleepy Time, Crip Time, See* and others will take up what Indigenous artist Elwood Jimmy has so adeptly outlined:

“Engagements and conversations about accessibility and disabilities mirror many of the problems we find when organizations attempt to include Indigenous and racialized bodies into modern-colonial spaces. Efforts to decolonize and Indigenize often address methodological and epistemological issues (i.e. ways of doing and knowing) without really tackling ontological issues (related to habits of being), where the issue of separability lies.”¹¹

Taraneh Fazeli

[Taraneh Fazeli](#) is an Iranian-American curator and writer living between Waawiiatanong/Detroit, MI and Lenapehoking/Brooklyn, NY. After a decade at NYC-based arts organizations, such as e-flux, Artforum, Triple Canopy, and the New Museum, Fazeli has worked as an independent curator since 2016. Taraneh’s curatorial practice engages art as a site to constitute reparative cultural rituals, interrogate the techniques of representation, and dream more-just ways of being together. She roots her approach to curating at the intersection of the disability, diasporic, and queer communities she calls home.

References

¹ Members of d/Deaf and hard-of-hearing communities expressed frustration online regarding the lack of ASL interpretation at the first Presidential debate of 2020. Since 2016, the Deaf Professional Arts Network (DPAN TV) has been providing live debate broadcasts with sign language and live captions. <https://www.hearinglikeme.com/how-to-watch-the-u-s-debates-with-sign-language/>.

² The Americans with Disabilities Act (ADA) was established as a US civil rights law in 1990 to protect the rights of disabled people. The ADA prohibits discrimination and requires reasonable accommodations be provided in transportation, employment, telecommunications, and public services. While its impact has been notable in removing some stigma and barriers in the built environment, its protections can be hard to enforce without legal support or bio-medical proof of disability. Furthermore, the legislation is one size fits all while disabilities are not. The limits of its value are taken up by the intersectional disability justice movement.

³ While the Roe versus Wade decision by the Supreme Court in 1973 protects a person's right to abortion without excessive government restriction, substantial obstacles still exist. These include prohibitive costs, individual state-level abortion restrictions which limit service availability, mandated waiting periods, and other factors.

⁴ The right to life is the belief that a human being has the right to live and should not be killed by another entity, including governments. The concept is not specific to abortion and comes up in debates on war, euthanasia, capital punishment, police brutality, and animal rights.

⁵ Harris raised the ban of these brutal tactics alongside committing to creating a national registry of police who break laws, getting rid of private prisons and cash bail, decriminalizing marijuana, and expunging criminal records associated with marijuana arrests or convictions.

⁶ Talia A. Lewis names Dustin Gibson and Black and other negatively racialized Disabled people as having been central to their development of this working definition. <https://www.talilalewis.com/blog/ableism-2020-an-updated-definition>.

⁷ The Republic of New Afrika (RNA) was founded in 1968 in Detroit. As a concept and organization, its framework incorporates radical Black nationalism, reparations, and African ancestry (the use of the "k" is in keeping with Swahili phonetic traditions). RNA centers the importance of land to power, advocating for the creation of a separate nation for Black people on the land of five Southern US states.

⁸ See speaks specifically of the complexity of people embracing disability in Detroit's Black communities and in hip-hop. In recognition of this, the biweekly care circles he facilitates in partnership with the nonprofit Detroit Disability Power and Healing by Choice are advertised for people with chronic illnesses not just disabilities. In hip hop, while numerous rappers—including J Dilla, Phife Dawg, and Heavy D—have died from complications related to chronic illnesses, they never laid claim to disability. While this could be attributed to mainstream hip-hop's prevailing "tough-guy" archetypes, it may also be due to not everyone having access to disability as an empowered status.

⁹ Jasbir K. Puar, *The Right to Maim* (Durham: Duke University Press, 2017), 66.

¹⁰ Press release by Will See, 2 November 2020. For more background on how Will See's music ties to organizing, see Taraneh Fazeli, "In Detroit, Artists Pursue Afrofuturist Visions of Justice and Afropessimist Strategies of Withdrawal," *Art in America*, Jul. 9, 2020, <https://www.artnews.com/art-in-america/features/detroit-artists-afrofuturism-afropessimism-1202693878/>.

¹¹ Thanks to Banff Centre faculty, curator, and disability studies scholar Eliza Chandler for turning me on to this important passage. She has written about the limits of accessibility practices that use universal design ideas versus those developed specifically with disabled people, in which she looks to Jimmy on access as rupture. Ellwood Jimmy, "Acces(sen)sibility," in *Translation Roundtable*, Arts Everywhere, <https://artseverywhere.ca/roundtables/translation/>.

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