

The “Swell”

Disability Arts in the Time of COVID-19

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We are New York City–based disability scholar/activists, founders/directors of NYU’s Center for Disability Studies, reflecting on our work chronicling the global COVID-19 pandemic and its impact on disabled people when our city became the US epicenter of this devastating illness. Endemic inequalities have structured the experience of the pandemic—especially for disabled people of color, the unhoused/uninsured, and those living in congregate settings such as prisons and nursing homes. In response, disabled artists and activists have summoned their long-standing expertise, offering social and infrastructural critiques and alternatives that underscore, in actor/playwright and disability activist Neil Marcus’s words, that “disability is an art—an ingenious way to live.”¹

This chapter considers how disabled artists have been making powerful claims on justice, displays of conviviality, and designs for remote access along with future possibilities for work, care, and civic participation. Disability artists and activists have responded to the COVID-19 crisis not only with heightened media advocacy and visibility; they have been reinventing the public sphere to come, offering distinctive models of art and community, created with and for non-normative bodyminds.

We examine how “living otherwise” has long characterized the innovation that disability demands, whether in the staging of daily life or on the multiple platforms that the arts provide, paying particular attention to exemplary creative approaches to challenging circumstances.² This volume’s title, “curating access,” raises important intertwined concerns: access for diverse disabled audiences, and opportunities for disabled artists making work shaped by what Tobin Siebers inaugurated as “disability aesthetics” in his groundbreaking 2010 book of the same name.³

Over the last decade, disability artistry has erupted, engaging the distinctive experience of living with disability, including the innovative integration of affordances in galleries, museums, theaters, community fora, and on stages and screens. As disability arts activist Kevin Gotkin comments:

I have been calling this moment a “swell” to describe the marked increase in attention for disability arts as an increasingly legible and

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transformative field without having to cede my wariness about its maintenance once it's revealed just how thorough-going the work of making arts accessible really is. A swell is a rush. It lifts. It is also liable to recede. The way we narrate this moment will determine what we think is possible and what we want next... These kinds of things are not access as an additive to art—they show us the ways that disability is a categorical intervention into what we understand art to be.⁴

In their 2020 introduction to *Contemporary Art and Disability Studies*, art educators Alice Wexler and John Derby note that:

Disability art spans a variety of cultural institutions, including art museums and galleries, community arts programs, disability organizations, and academia [as a] ... confluence of artistic representations in multiple forms and media [that have] disrupted the white, abled dominance of the art world.⁵

In short, the impact of the disability arts movement far exceeds the boundaries of arts institutions. Disabled artists curate cities and digital spaces differently. In a 2020 article, legal scholar Elizabeth F. Emens argues for the crucial influence of disability art on “attitudes to the implementation of disability law” beyond the model of minimal compliance.⁶

Since 2010, disability arts have proliferated new aesthetics and a more inclusive sense of cultural citizenship. Consider the words of this book's editor, Amanda Cachia, a noted art historian, disability activist, and curator of numerous exhibits focused on disability artistry that directly engage and cripple the humanist tradition. In the catalog for her vanguard 2012 curated show, *What Can a Body Do?*, she asks:

What does it mean to inscribe a contemporary work of art with experiences of disability? What shapes or forms can these inscriptions take? How, precisely, can perceptions of the disabled body be liberated from binary classifications, such as “normal” versus “deviant” or “ability” versus “disability” that themselves delimit bodies and constrain action? What alternative frameworks can be employed by scholars, curators, and artists in order to determine a new fate for the often stigmatized disabled identity?⁷

We explore these issues as they emerged for the disabled artists whom we encountered during the pandemic and the solutions they created. These include award-winning dancer and choreographer Alice Sheppard's call for disability creativity with her company Kinetic Light's pandemic-inspired, crowd-sourced project, *#QuarantineShorts*, as well as their film *One + One Make Three*. Other collective projects brought people together online in

a variety of *dismediations*, a term Jonathan Sterne and Mara Mills use to describe “disability as method”—a theory of “media change and technical design” from a disability perspective.⁸ Critical Design Lab’s Aimi Hamraie and disability nightlife doyenne DJ Who Girl (a.k.a. Kevin Gotkin) threw the inaugural *Remote Access Party* in March 2020, reminding invitees that “Disabled people have long used remote access as a method for organizing pleasure and kinship. We call forth our community for an afternoon and evening of pleasure activism through crip nightlife praxis and #CripRitual.”⁹ We also highlight Poets of Course, Outside Voices, and Isolation Nation, an overlapping network of spoken word/writers/artists with intellectual disabilities (ID). Their pandemic projects led to a collectively produced film, *Isolation Nation*. Additionally, we consider Heidi Latsky Dance, an integrated dance company creatively facing the catastrophic cliff of nonsupport when public performances were shut down in New York City and elsewhere. Finally, we engage disability activist/designer Jen White-Johnson’s striking graphic art. Her work rendered #BlackDisabledLivesMatter powerfully visible, part of racial justice claims marking the intersecting public crises and aspirations that mobilized a crosscutting coalition of activists.

These productions are reminders that the high learning curve of the present is continuous with the interventions of disability arts prior to the pandemic. Amplified by the exigencies of living under lockdown, these disabled artists are curating access across institutions and digital platforms, where we hope the “swell” of attention to access will prove to be enduring.

Choreographing Remote Community: Alice Sheppard and Kinetic Light

As many cities required social distancing which suspended public performances, the disabled choreographer, dancer, and activist Alice Sheppard, founder of the dance company Kinetic Light, reached out to far-flung disabled friends and followers via social media. She urged them to join her online project, *#QuarantineShorts*, by uploading short videos made under the new exigencies, in order to become part of a collective project.

We know that many of our disabled beloveds have been severely affected by the crisis, and we are troubled by the ways that disabled people’s futures are so at risk. We also know that many of you already have deep knowledge of the practices we are calling “shelter-in-place” and social distancing; we know you already know about lack of access to public space and resources... .

While in-person activities are cancelled, we’ve been able to create and play a little, remotely, with what we’ve been calling *#QuarantineShorts*. We’ve seen creations in kitchens, in bathrooms, and outside. You have sent responses from New York City, California, the U.K., Vancouver,

France, and beyond. We love them all. This project is open to all artists and creatives.¹⁰

#*QuarantineShorts* conjured a remote yet embodied conversation among disabled dancers and artists: one person offers a prompt—for example, *widen*—and others respond with movement. The series provides glimpses of disabled life under quarantine, from the mundane to the surreal. A twenty-four-second video shows dancer Jerron Herman on his side in bed, staring intimately at the camera, telling the viewer in (captioned) voiceover, “A brown comfy comforter lifts up in the air above a brown skinned face.”¹¹ In another, Sheppard dances in her wheelchair in the crook of a giant oak tree, an enchanting dramatization of open-air quarantine with wind and birdsong.¹²

By November 2020, Sheppard assembled her Kinetic Light team—disabled dancers Laurel Lawson and Jerron Herman—to create the docu-dance film *One + One Make Three*, chronicling the group’s work together on a new project for the All Arts Past Present Future Festival (see Fig. 1.1). The festival invited choreographers “to work with filmmakers of their choice to explore through movement and film what the concepts of past, present, and future meant to them during an unprecedented year.”¹³ In the film, we see the Kinetic Light team collectively experimenting with choreography for their dance-in-progress, *Wired*. We hear them speak mostly via voice-over, addressing the aesthetics of their joint work. We witness astonishing aerial work with and without wheelchairs, the constraints of movement with barbed wire, and the interactions among the dancers that are foundational to the creative, interdependent crip sensibilities of Kinetic Light.¹⁴



Figure 1.1 Kinetic Light, *One + One Make Three*, 2020. Still Photograph by Melvin Edwards, Courtesy of One + One Make Three/Safety Third Productions.

Alice introduces the first section of the film, “The Present,” grounding it in the pandemic: “It is November 2020. It is in the middle of the COVID pandemic. The world has broken apart.”¹⁵ The narration of the dancers throughout the film is available in open caption, closed caption, and American Sign Language, as well as a transcript. Additionally, a rich audio description track gives a sense of the documentary’s visual *mise-en-scène* for blind or low-vision audiences. Laurel Lawson’s narration underscores creative strategies for “curating access”:

Kinetic Light is deeply invested in aesthetic, equitable, artistic accessibility as an essential part of our work... We craft these accesses as integral to our art, grounded in our user research and in collaboration with other disabled artists, and our offerings are intentionally allowed to be challenging, provocative, overwhelming and beautiful. Equitable accessibility of art must be as complex and engaging as the work demands.¹⁶

In response to film director Katherine Helen Fisher’s query, “What do we need to know about disability and access?” Alice answers:

The first thing I think the nondisabled world is going to think about is that the wheelchair becomes a choreographic object when it is not. It is my body, and it is not a prop, it is not a tool, it is not a device, it is not an extension of my body. It is my body.¹⁷

Laurel picks up the discussion.

Dance as ... the artistic cultivation and expression of the body is in many ways ideal for the disabled body because we inherently have something different to say. Now, I cannot compare, having never been nondisabled, uh—cannot compare what it might be like to dance in a nondisabled body.¹⁸

Alice responds:

The goal here is not to sort of set in opposition, but to see how the field of dance for disabled artists is expanding: how it can grow. To really live out a perspective where disability is not incidental, but is part of a culture and aesthetic in itself.¹⁹

This metacommentary is the spine of the film, capturing the foundational creative commitment to the inseparability of access and artistry in Kinetic Light’s choreography and performance. It also provides a rich understanding of the sensibility of a collective project built on faith, trust, and love among these dancers. This experiential aesthetic of community building

across a variety of media is a consistent thread in the works of the other disabled artists who we discuss.

Parties as Crip Technoscience: The Critical Design Lab's Remote Access

Other collective projects brought people together online synchronously, extending the tradition of disability-centric parties into the digital sphere through multimedia access tools and human “access roles.” Critical Design Lab’s participation guide for the *Remote Access* Crip Nightlife Gatherings—launched in March 2020 and evolving across a half-dozen parties since then—assumes that on Zoom “things will not work perfectly.”²⁰ Alongside captions, the chat box is used for crowd-sourced descriptions of sounds, responses to song lyrics, and comments on the “aesthetics and mood” of the DJ. At each event in 2020 and 2021, some partygoers volunteered to be “access doulas,” providing general troubleshooting and answering participants’ questions.²¹ During the parties, people dropped in and out, danced, tried on clothes, lay in bed, kept their video off, chatted, were alone on camera or not. Artist Yo-Yo Lin created slides with abstract visuals for the first event, audio-described by volunteers over a parallel Zoom channel to which people could call in.

In June 2020, at the height of the Black Lives Matter protests in the United States, Critical Design Lab created a solidarity guide of “design commitments to abolishing white supremacy,” with eight design justice steps for recognizing racialized ableism, marshaling “disabled world-building” toward “new infrastructures and ways of living.”²² Hamraie also created a *Remote Access Archive*, curating examples of disability communication and connection.

During the COVID-19 pandemic, many people are learning and working by using technologies such as the phone or internet. This is sometimes called “remote access.” But before the pandemic, when disabled people asked for remote access, they were often told ‘no.’ People said that remote access costs too much money or is too hard to do. But remote access is important for disabled people. It is how many of us live, socialize, and organize.

The Critical Design Lab is creating an online archive of the ways disabled people have used remote access before and during the COVID-19 pandemic... . *The Remote Access Archive* will gather stories, documents, and other information about how disabled people have used technology to interact remotely.²³

More than a dance party, *Remote Access* became “an enactment of crip technoscience through disability culture as a political act of mutual aid”—while

acknowledging the long disability history that underpins new media platforms and forms of community.²⁴

Crip Funds: Work, Mutual Aid, and Artist Relief

Other projects offered immediate pragmatic interventions aimed at financial aid.

Ninety-five percent of artists lost significant income during the pandemic, and disabled artists—already underrepresented, if not outright excluded from the mainstream art market—were particularly at risk.²⁵ In March 2020, even before New York City shut down, a group of disabled and chronically ill artists organized Crip Fund, pooling money and distributing food, medicine, and other aid to “immunocompromised and disabled people in need of in-home care,” noting that “QTBIPOC (Queer/Trans/Black/Indigenous/People of Color) will be prioritized.”²⁶ Crip Fund ran through GoFundMe for just one month, setting an initial goal of \$20,000 that donors nearly tripled. In an irony of the platform, when the campaign ended, the home page was automatically tagged with the alert: “The organizer has currently disabled new donations to this fundraiser.”

Themes of debt and financial precarity are frequent in the work of the artists behind Crip Fund.²⁷ While mutual aid became one of the buzzwords of the pandemic, the intentional brevity of Crip Fund reminds us that public institutions and the state should not be relieved of caring for citizens and compensating cultural work.²⁸ The 1935 passage of the Social Security Act brought the United States—kicking and screaming—into the “modern” era of unemployment, old age, and disability benefits in the midst of a Great Depression that left one in three residents of our own city unemployed, while “Hoovervilles” of improvised shacks sprang up in Central Park, along the riverbanks, and around NYU where we now work.²⁹ Social insurance has steadily eroded in recent years, not offset by solidarity or charity movements.

In 2021 many cities, states, and philanthropic organizations announced relief plans for artists, modeled on the New Deal—although smaller in scale and more temporary—to supplement federal relief for this vulnerable sector of the economy. A New York State report from February 2021 estimated that the arts, entertainment, and recreation diminished by 66 percent during the pandemic.³⁰ In response, New York City launched City Artists Corps in May, providing grants, mural commissions, and educational partnerships totaling \$25 million.³¹ Additionally, the Mellon Foundation announced a \$125 million Creatives Rebuild New York (CRNY) plan to offer either “guaranteed income” or employment to over 2,000 artists in New York State. Although none of these funding campaigns explicitly references disability or accessibility (at least initially), the CRNY “think tank” includes one of the organizers of Crip Fund, among other disability artists,

suggesting that the “swell” is influencing municipal responses in the realm of arts funding.

Finding Poetic License: Outside Voices, Poets of Course, Isolation Nation

Community support and solidarity can be literally lifesaving under pandemic conditions, especially when governmental resources were scarce-to-nil early in the pandemic. Consider Outside Voices, a theater company for/ by people with ID that evolved from a funded day habilitation program toward a far more radical critique of discriminatory ableism.³² Its website proclaims, “If you have come here to help me you are wasting your time, but if you have come because your liberation is bound up with mine, then let us work together.”³³ Its mission statement explains its commitment to disability justice:

Outside Voices Theater Company wishes you to know the following: We are about advocacy, empowerment, out-of-the-box-thinking and disability pride. We chose our name because we believe that VOICES from the OUTSIDE deserve to be heard. We believe in access. We will not use our quiet, inside voices to get your attention.³⁴

Many members overlap with Poets of Course, a weekly writing group whose members have ID.³⁵ Their poetry has been published and participants perform at citywide poetry festivals. Outside Voices’ face-to-face activities of poetry-writing-turned-into-scripts have led to videos often commissioned for counselor training and live performances. Both groups quickly turned into online support systems as members were physically separated from one another by the pandemic. The twenty or more members regularly in attendance are quite diverse; some live in congregate housing, others share an apartment with supervision, while some are at home as adult children of aging parents, and a few live independently. When the virus hit, members worried about one another. Some quickly brought in friends from other programs for people with ID, welcoming new peers under COVID exile. Remarkably, the groups are thriving, responding to expressions of distress, sending texts and poems as reminders of one another’s valued membership in this morphing community at a perilous time. Support staff for Outside Voices’ members have become more active, checking up on one another, sharing apps and supplies, and contributing their poems to group readings, thus melding the cared-for and caregivers. When one non-speaking long-time participant noted with his word board, “my inability to speak, called silence now leaves me so so lonely,” a deluge of phone texts arrived—since this valued member can’t respond to phone calls, the primary connection many others were using.³⁶

Isolation Nation evolved from these long-term workshops for writers and performers with ID who were recruited for a six-week project, to represent in their diverse media the experiences of before-during-after the pandemic. Their goal was to publicize the creativity, insight, and artistry provided by those who are too often stigmatized and ignored. Isolation Nation was supported by JobPath, an offshoot of the Vera Institute of Justice's foundational work helping people with developmental disabilities join the workforce. The group produced a film, *Isolation Nation*, that included their poetry, drawings, sculptures, music, and mixed media, currently on the website of New York City's Parks Department and YouTube.³⁷ It will eventually appear with audio description and surrounding biographies of each artist on the Positive Exposure 109 YouTube channel founded by Rick Guidotti, an eminent photographer of people who have been stigmatized and bullied for their disabilities/differences.³⁸

Isolation Nation's production process taught us that curating access has capacious, open, and multiple meanings. Beyond captioning and audio description, they added an access feature of their own: one member runs a business with his best friend and wanted it listed after the credits to encourage commercial outreach. Following his lead, other members added their websites, gallery representation, and YouTube channels to enhance their public visibility and financial opportunities, extending such access as an aspect of living otherwise.

Displaying Difference on a Global Stage: Heidi Latsky Dance

Mutual support took a different shape in the integrated professional dance troupe Heidi Latsky Dance (HLD).³⁹ When scheduled performances and commissions abruptly stopped, HLD mounted weekly online meetings, keeping dancers together. Choreographer Heidi Latsky offered open Zoom sessions that focused on the breathing and centering technique she developed for herself and her dancers with diverse bodies; these helped everyone engage new vocabularies of choreography and virtuosity. Over many months, weekly sessions also brought dancers and resources together: meetings ranged from the politics of integrated dance to visits with foundation officers who discussed resources for the arts during this financially catastrophic shutdown. Maintaining contact and courage during these harrowing times was a primary form of mutual support.

These activities bolstered a floating community of dancers, nurturing a loose network of people connected to the troupe. HLD also faced outward: beginning in 2015, Latsky presented a dramatic evolving performance piece that mobilizes diverse dancers into a living sculpture garden; audience members are encouraged to stroll through. Based on her breathing and slow movement techniques, *On Display*, retitled *On Display Global* (ODG), quickly expanded

from its initial NYC setting at the United Nations—where it had been incorporated into the UN’s annual celebration of “persons with disabilities” every December 3—to a 2020 mega-Zoom event held across seventy-eight international sites, ranging from Australia to South Korea and Lebanon.

Latsky has taught her techniques to an array of local dancers who serve as ambassadors, recruiting performers and non-professionals, disabled and nondisabled, highlighting the bespoke white costumes and site-specific settings to celebrate this international day of recognition in their own appropriate locale. At an online reunion of ODG participants in June 2021, shared testimony included moving descriptions by adults with ID in the small town of Arezzo, Italy, whose marginalization was challenged when the mayor and city council turned up to welcome their performance. Disabled dancer-organizer Rosa Weinberg reported on staging ODG in both Mexico and Chile: “Who we are, here and now, is visible,” she proclaimed. Anderson Carvalho, a disabled Brazilian dancer living in Amsterdam, organized an ODG event at which he and his colleagues “felt free, connected to the world” through dance.⁴⁰ Latsky envisions an ever-increasing set of technical affordances for the films, museum displays, and stage performances she creates. ODG provides a platform for a dramatic virtuosic enactment inclusive of disability, enabling a shared utopian moment with widened access, if only for one day each year.

Designing Disability Justice: Jen White-Johnson, #BlackDisabledLivesMatter

Graphic design has been central to the disability justice movement. We highlight the work of Jen White-Johnson, a disabled artist, photographer, parent of a neurodivergent boy, and professor at Maryland’s Bowie State University.⁴¹ The summer of 2020 was shaped by not only the pandemic but also the violent deaths of George Floyd, Breonna Taylor, Rayshard Brooks, and many other Black people who were the victims of police brutality. Artist White-Johnson created a striking icon: a raised Black Power fist with the infinity symbol—a positive sign for neurodivergence—and the words “Black Disabled Lives Matter” inscribed on the wrist with a bold sans serif font (see Fig. 1.2)⁴². As she explained in an interview with disability activist Alice Wong:

I wanted to take type and digital illustration and merge them to say something strong, to create some sort of unifying symbol or visual. I thought of the Black Power fist because we’re talking about Black disability and disability justice, and this is a frickin’ revolution, you know?⁴³

Her open-access graphic rapidly went viral, appearing at BLM and other protests all over the world, building a sense of solidarity that encouraged



Figure 1.2 Jen White-Johnson, Black Disabled Lives Matter Logo, 2020. Poster Design by @jtknoxroxs. Jen White-Johnson, <https://jenwhitejohnson.com/Free-Printable-Black-Disabled-Lives-Matter-Poster-Print>. Image Courtesy of the Artist, Jen White-Johnson.

action on the part of the #BlackDisabledLivesMatter movement, giving it greater visibility. On her website, White-Johnson writes:

More than half of black/brown bodies in the U.S. with disabilities will be arrested by the time they reach their late 20s... . The graphic has been instrumental in reigniting much needed dialogue about Black Disability Community.⁴⁴

Recollecting her experience at her first BLM protest, White-Johnson was thrilled to see her graphic on posters and “how people pasted them on

cardboard with their own messages along with stories of disabled folks who have been victimized and brutalized by the police: Freddie Gray, Sandra Bland, and Laquan McDonald.”⁴⁵ Downloadable access from White-Johnson’s website meant that this groundbreaking graphic was widely seen, bringing public attention to the intersectional challenges of living Black disabled lives under conditions of widespread racism and police violence. Jen White-Johnson’s graphic talents have rallied people to the cause of disability justice, enabling us to reimagine disability publics in ways that refuse to separate access from aesthetics—an approach that characterizes the work of all the disabled artists we discuss.

Living Otherwise

Disability artistry during the pandemic demonstrates the possibilities of living otherwise, revealing the creative entanglement of access and aesthetics. Working in many media, disabled artists have been at the forefront of protests, mutual aid, and digital worldmaking, while addressing the long-standing failures of economic and civic infrastructure, imaginative as well as practical. In our epigraph, Kevin Gotkin calls this transformation in disability arts a “swell,” adding, “The way we narrate this moment will determine what we think is possible and what we want next.”⁴⁶ These words help us remember what disabled artists have catalyzed during the pandemic, the labor involved, and how easily this “swell” of attention to accessibility—both online and off—could recede.

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