

A TEMPORARY, COLLECTIVELY-HELD SPACE

A conversation between Amanda Cachia
and guest-editor Carmen Papalia

In this summer issue, guest-edited by Carmen Papalia, writers, artists, and other cultural producers have been invited to reflect on disability, art, and access. The issue is produced in tandem with the exhibition, *Provisional Structures: Carmen Papalia with Vo Vo & jes sachse*, on display at the MacKenzie Art Gallery in Regina, Saskatchewan, from 12 June – 17 October 2021, and curated by Nicolle Nugent. The exhibition is a culmination of a three-year collaboration between the gallery and Papalia, who have been working together to develop a comprehensive accessibility policy for the gallery that is meaningful and long-term.

In addition to this issue, the exhibition, and the access policy, which builds on Papalia's long-standing *Open Access* research, this wide-ranging project also encompasses multi-faceted public programming that can be explored on the MacKenzie Art Gallery website. For the introduction of this special issue, Papalia invited independent curator and art historian Amanda Cachia to engage in a conversation with him regarding Papalia's exhibition, the highlights from the issue, and how disability art has evolved in the past ten years since they first began collaborating in their relationship of curator/artist in 2011.

Amanda Cachia: What was your motivation behind doing this special issue of *BlackFlash*?

Carmen Papalia: When Nicolle Nugent, the Curator of Education at the MacKenzie Art Gallery, approached me about working on this special issue of *BlackFlash*, it was in the context of my exhibition at the MacKenzie called *Provisional Structures*, which opened this June. I've been working with the MacKenzie for over three years now; my friend and mentor David Garneau introduced me to the gallery in 2017.

I visited the MacKenzie a couple times a year and did some programming there too. I've conducted my "See for Yourself" eyes-closed museum tours there, as well as touch workshops with objects from the collection. During every visit, I worked with a cross-section of staff from different departments and levels of management. We held workshops and facilitated dialogue on accessibility framed by the principles of Open Access, a manifesto I wrote in 2015.

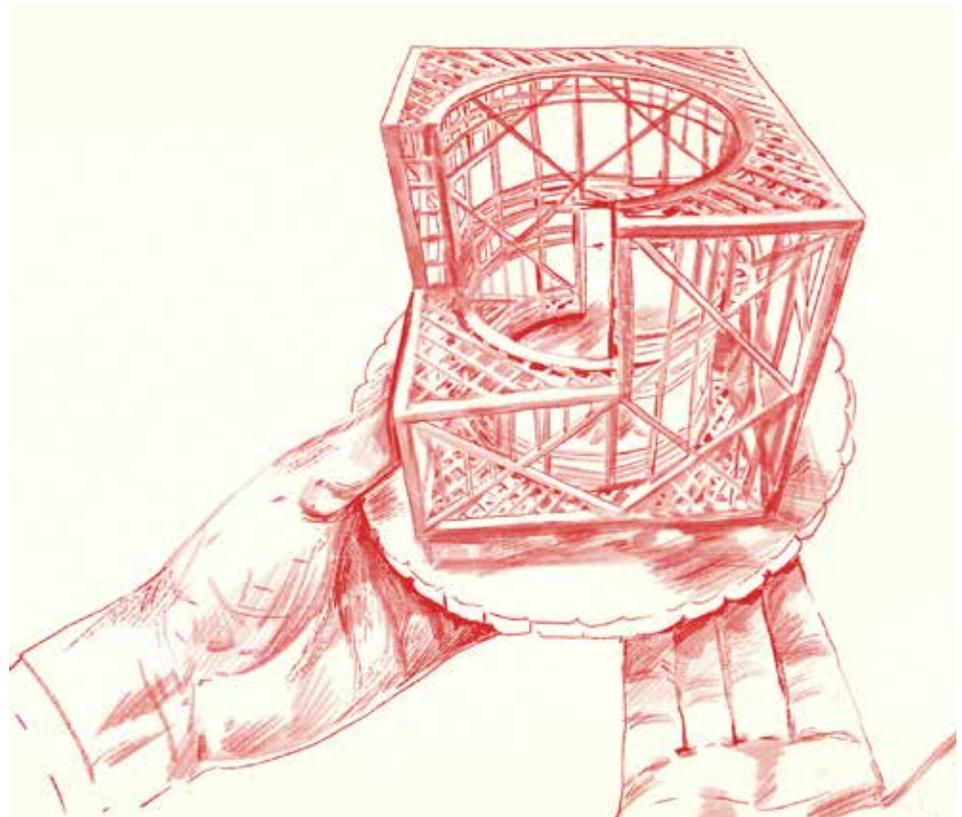
More recently, we looked at Indigenous and colonial organizing principles in relation to the museum's design, a

Page 2: Carmen Papalia, *Provisional Structures*, 2021. Schematic drawing by Micheal Lis, Good Weather & Associates.

A black and white photo of the spiral ramp model made of paper with pins all along the inner and outer edges of the ramp to act as the scaffolding. The model rests on a schematic drawing showing the dimensions of the exhibition hall the spiral ramp will occupy, and that sits atop a lined, ruled cutting mat. An artist rests one finger lightly on the ramp to hold it still as their other hand reaches in with an X-Acto knife to refine a cut.

Page 3: Carmen Papalia, *Provisional Structures*, 2021. Animation by Heather Kai Smith, 2021.

Two hands extended forward, palms up, drawn in red pencil. Resting on the hands is a 3-D architectural model of a tall exhibition hall, the space filled by a 12-foot-high spiral ramp with scaffolding around its edges. The walls and ceiling are rendered in only the latticework of their beams. The ceiling is wide open directly above the spiral ramp.



project spurred by our reading of “Bricks and Threads” by Elwood Jimmy and Vanessa Andreotti from their 2019 book *Towards Braiding*. We also looked at the principles of disability justice and trauma-informed care, reading texts like “Access Intimacy: The Missing Link” by Mia Mingus and the writing that Nick Walker has done on neuroqueering and neurocosmopolitanism. Spending time with this material was paramount to the MacKenzie’s production of a new accessibility statement. It was a long process that is now finally public. In addition to [collaborative] consultations with myself, the MacKenzie staff also sought guidance from David Garneau, Peter Morin, local elders, and representatives from local organizations dedicated to disability justice.

One of the pieces in this issue is by artist Vo Vo, an Oregon-based fibre artist with over eleven years’ experience providing training that approaches trauma-informed care through the lens of disability justice. I saw Vo speak as part of the Portland Disability Justice Collective’s conference in December 2020 called *As We Are: Disability Justice and Community Care*. Vo was one of the keynote speakers at that gathering. Their talk spoke to me at a cellular level.

Recently, I have been working through my own experience of medical trauma. I have spent a significant amount of time in hospital since childhood and still heavily rely on the medical system to address my severe complex pain condition. I started reflecting on my own medical trauma last summer. Now, in socially safe spaces, I identify as someone with medical trauma, which originated from the numerous failures I experienced when needing emergency medical care. I am starting to trust my medical providers again despite holding distrust from previous experiences, but my trauma still gets triggered every so often. When receiving my first dose of the COVID-19 vaccine, my name had been misspelled in the database. When the attendant called for their supervisor, I immediately had a panic attack and started crying. I was scared that I wouldn’t get the vaccine, even though I’m one of 200,000 people in my province considered clinically extremely vulnerable.

Hearing Vo’s talk was the first time I heard someone link disability justice with trauma-informed care. I decided to include the audio from Vo’s keynote as the centrepiece of my installation at the MacKenzie Art Gallery. The installation is fairly monumental in scale. It’s a spiralling accessible ramp



Carmen Papalia, *Provisional Structures*, 2021. Schematic drawing by Micheal Lis, Good Weather & Associates.

A black and white photo of artist Carmen Papalia sitting on a covered patio, smiling broadly. He leans forward, arms extended, both hands within a 3D model in wood, balsa, and metal that rests on a wicker table in front of him. The model has three of its four walls, representing a space over twelve feet high. Within, a wooden spiral ramp rises toward the top of the model, held in place with tall metal stakes for scaffolding. Above the open centre of the spiral, a ridged wooden dome hangs from a wire. Just beneath the hovering dome and within the centre of the spiral is a circle of tall rectangular columns with wooden frames, which are mirrored on the sides that face into the circle. A set of sand bags used for disaster relief create a circle along with the mirrored columns and have been repurposed into low sitting benches.

made of scaffolding materials that reaches over twelve feet tall. There is a seating and gathering area on the ground level, and from the ceiling above hangs an acoustical dome that focuses the acoustic space by differentiating it from the rest of the gallery. The seating in the gathering area is made out of sandbags that are arranged as a semicircle, referencing disaster relief. The bags are printed with a stencil that says "open access." Vo's talk plays periodically in that circle.

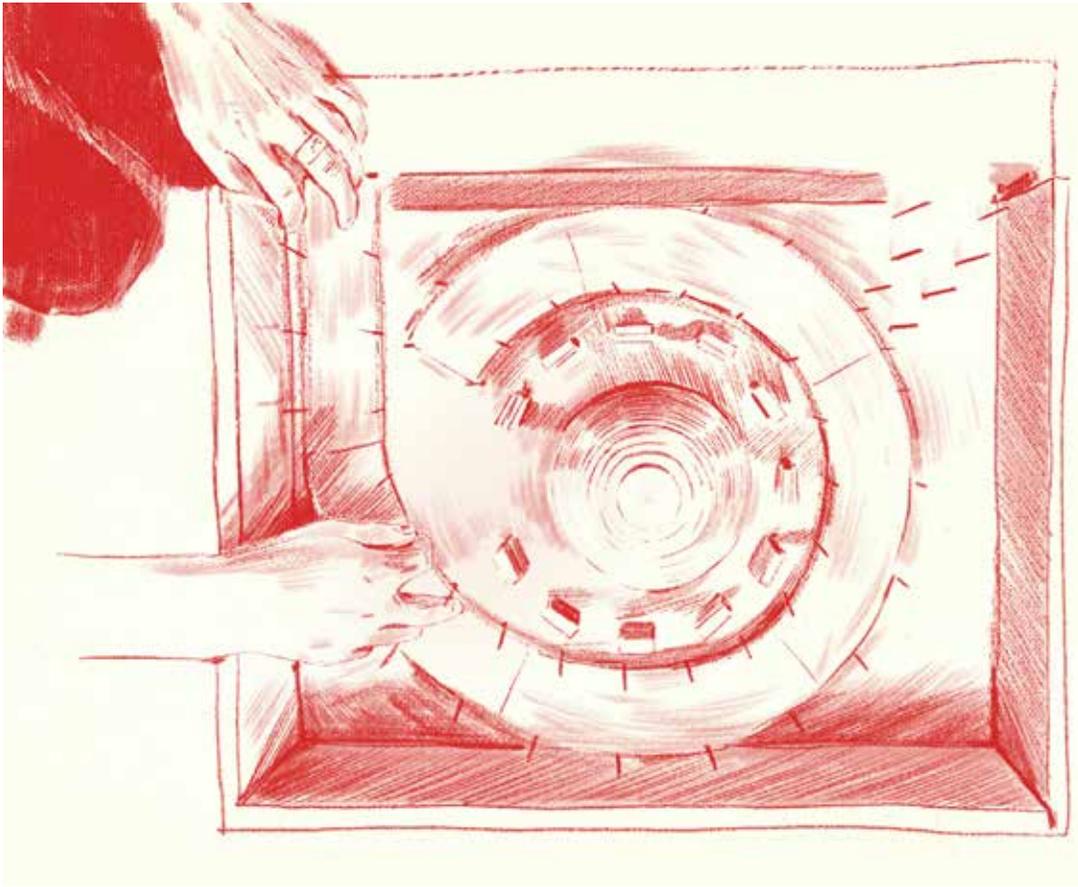
I've been trying to define accessibility beyond compliance-level measures for a long time, and learning about Vo's trauma-informed approach to disability justice has been so helpful in advancing my thinking on the topic. I believe that trauma-informed care was the missing piece when trying to describe accessibility beyond accommodation, especially when thinking about accessibility that is guided by relationships.

At one of the entrances to the gallery there is also a work by jes sache. It is a series of over 800 bronze plaques that reference the donor walls that are often at the entrances of museums. Engraved on each plaque is the phrase "I need a minute", a request for more time, more consideration,

slowness, maybe more compassion and understanding around an access request. It assumes that things are moving too fast, asking that we slow down to check in, reassess and readjust around the terms outlined by the person asking for more time.

I discovered jes's work before I started the Art & Social Practice MFA program at Portland State University in 2010. Their work and advocacy set a context for my work in the Canadian art landscape. I really appreciate the way jes approaches institutional critique, and the playfulness of their interrogations. My sense of most of jes's work with institutions is that they are looking for a respectful relationship based in trust, where they and their access needs are understood around their terms. This requires whoever is hosting them to take the time to get to know them and build that relationship, which is a deeper commitment than the typical transactional art relationship.

Amanda: Your exhibition at the MacKenzie seems like a continuation or an evolution of what you did at Banff Centre for the Arts in 2019.



Carmen Papalia, *Provisional Structures*, 2021. Animation by Heather Kai Smith, 2021.

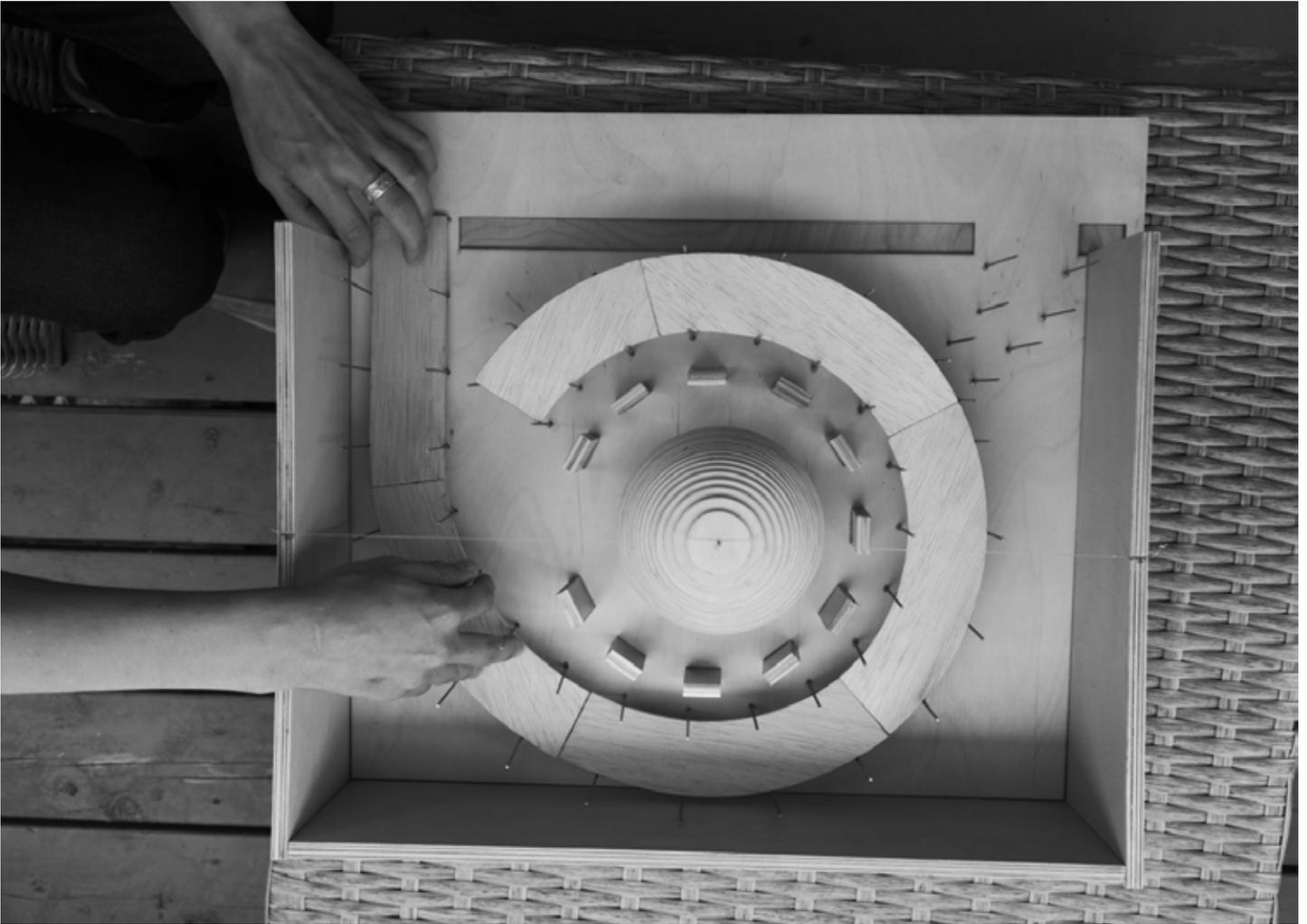
A view from above looking down into an architectural sketch in red pencil of a 3D model of a spiral ramp. The model ramp is within a box with an open top. A person sits by the model, hands resting on the edge of the box.

Carmen: Yeah, this show is definitely an evolution of my exhibition with Heather Kai Smith called "Guidelines," which showed at the Walter Phillips Gallery at the Banff Centre in 2019. For the Banff show, there were mirrors arranged at thirty-, sixty- and ninety-degree angles, a choice I made in order to create a disorienting visual experience for the sighted viewer. There was also an implied path through the mirrored pillars in red string. I developed that strategy when Megan Arney Johnston brought me to The Model, a contemporary art centre in Sligo, Ireland, in 2015. That was the first time I used red string in an installation—it indicated my most frequently travelled routes through the gallery and served as a tactile wayfinding tool. The exhibition at the MacKenzie is probably the most involved installation I've made and brings together threads from previous work.

Just like the new standards of care that have emerged in the time of COVID-19 and the Black Lives Matter uprising, disability justice needs to be the new standard for how we understand accessibility in this new cultural landscape. This is something that the recent organizing in opposition to Bill C-7, the Medical Assistance in Dying Act, helped clarify for me.

I'd like to point to the interview that Kay Slater did for this issue. Kay interviewed a young disabled activist and organizer in British Columbia named Q Lawrence. Q worked directly with Catherine Frazee and Gabrielle Peters, the main instigators of the anti-MAID organizing. Q was behind the scenes, managing the backend of the virtual space and serving as host at points throughout the Disability Filibuster livestream.

Gabrielle started the site Dignity Denied, a hub for information about the harm of C-7. She is a poor, disabled BC resident who is on disability assistance. What Gabrielle has shared through Dignity Denied really points to the majority experience within the broader disability community: of being poor and perpetually at the whim of harmful and insufficient government programs. The experience of being poor and on disability assistance is something that still doesn't get enough space in conversations about accessibility; having one's agency and autonomy stripped by those in positions of power isn't widely understood as a barrier that disabled people face. I have to thank Catherine, Gabrielle, and their co-conspirators for dedicating a platform to this class analysis of disability.



Carmen Papalia, *Provisional Structures*, 2021. Schematic drawing by Micheal Lis, Good Weather & Associates.

A black and white photo of the wood and metal spiral ramp model on the wicker table from above. Carmen's hands reach in. One hand slips in through the missing fourth wall of the model, a finger set lightly on the ground-level entrance onto the ramp. The fingers of his other hand traverse the ramp as it ascends and spirals around. The dome held aloft by wire floats above the centre of the model, and the set of tall mirrored columns circles the dome. The ramp creates a third circle. A set of metal stakes at regular intervals hold the ramp in place as scaffolding, and a second set outlines a path from the edge of the open wall directly toward the centre area of tall columns.

I was actually lucky enough to present as part of the Disability Filibuster livestream before C-7 passed via royal assent on March 11, 2021. I presented with my friend Aislinn Thomas, and we talked about disability justice and disability as political identity. We also shared some of our prior experiences with medical ableism and ableism in general, as well as the hope we've found working in community with other disabled people.

In her statement that was read on the Disability Filibuster 2.0 stream, Gabrielle identified that the medical system is harmful to us as disabled people. I agree—I would say the medical model of disability is completely incongruent with the disabled body and mind, and was built in an effort to erase us.

In BC we have a history of deinstitutionalization and examples of self-determined disability-lead support networks that communities established for themselves in response to governmental failure, medical ableism, and policing. After the institutions closed, organizations like the Mental Patients Association sprang up, and later, overdose prevention sites in Vancouver's downtown eastside were set up by drug user activists.

The filibuster pulled these largely unknown activist histories into the spotlight, with the recognition that disabled people have always been banding together in order to survive. The filibuster was a reminder that there are a lot of us, that there is power in numbers, and that we can't just settle for the insufficient support that a government or health authority provides. It marked a significant moment in the history of disability activism: the moment when disabled, d/Deaf, hard of hearing, mad, neurodivergent, sick, and chronically ill people across the country realized that disability culture is a counterpoint to the violence of ableism.

It was this momentum, and the principles of disability justice, that inspired me to bring this group of artists together to write for this issue.

In Aislinn Thomas's piece, she explores why artists labelled with intellectual disabilities aren't included in the Disability Arts, and uncovers some of the patronizing care dynamics that exist at studios where artists labelled with intellectual disabilities work. The dynamics between caregivers and those who require care echo the harm of the medical model of disability, a direct connection to institutions where, prior to the broader independent living movement, people with high care needs were held. Thomas interviews artists and arts workers who challenge the biases within the wider arts landscape that continue to permit "acceptable" disabled artists who don't cause much of a disruption to advance within the field.

Amanda: You and I have known each other for, when did we meet—2011? So, we've known each other for ten years. I'm wondering if you feel like things have evolved and changed

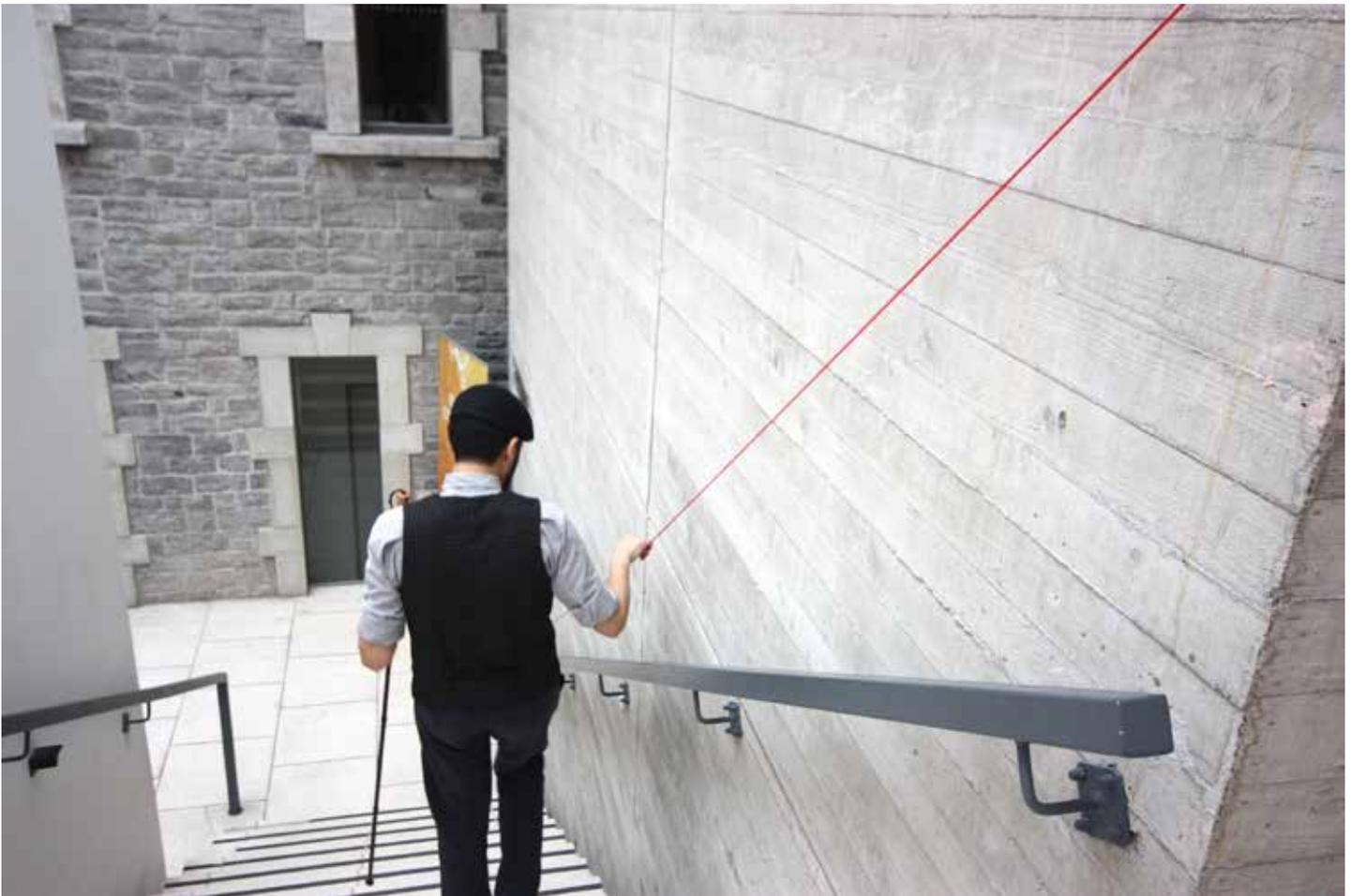
in disability art, disability culture, and activism in the ten years since we've met?

Carmen: I think there's more of an awareness within the wider non-disabled public that disabled people and disabled artists exist, but I think there's still a severe lack of representation when it comes to disabled people serving in decision-making roles. There's more visibility now regarding our movement and our work, but still a limited cultural understanding about what it means to be disabled and to live under ableism and its intersections. We need more representation in cultural platforms, and we need cultural institutions to take our leadership, so that our culture and history is represented on our own terms.

We're witnessing a moment where institutions claim to be dedicated to equity and inclusion and diversity, but they still haven't really meaningfully included us. We're still waiting for a culture shift when it comes to how we're perceived as a group. I believe the principles of disability justice provide solid guidance for how we can get there.

Amanda: I'm curious if you think there are more disabled artists making work about disability now. It seems people are feeling more comfortable identifying as disabled to begin with, and making work about their experiences not only with a specific physical or intellectual disability, but with medical ableism as well. That seems to be a significant topic for younger-generation artists and within disability activism at large. There are more people engaging in activism and have spoken out. I see more funding for disability arts as well—through the Canada Council for example—and it's really amazing to me that this has happened.

Carmen: Yeah. You're right, there are more artists and activists engaged in these practices, and there's more awareness of where they are and who's out there, and maybe more connectedness online within dedicated platforms and intentionally held spaces. I remember ten years ago I was still trying to find my way into museums as a disabled artist. My entrance was through the education department. I was really trying to figure out how to break down the wall between education and curating. I don't know if younger disabled artists are concerned with gaining access to those platforms anymore, because there's so many affirming disability-lead platforms now. I think there's also this awareness that institutions are sites of colonization and traumatization. Disabled artists have to negotiate with museums for basic care and consideration, something that should be automatically practiced by museums hosting artists whose work they benefit from. So, I can imagine that younger disabled artists would just rather work within their community context where they're supported and understood. Maybe that's why we are organizing right now...while we've been super vulnerable during the pandemic, we're pushing for bold changes. Disabled people are envisioning the futures they want and organizing toward them together. It's exciting to witness this self-determination. We're world-building



Carmen Papalia, *Red String* (installation view), 2015 - ongoing. Installation at Model Contemporary Art Center, Sligo, Ireland. Dimensions variable. Photo by Kristin Rochelle Lantz. Image courtesy of the artist.

A view from above looking down at artist Carmen Papalia from the back. He is halfway down a flight of stairs and gently touching a red string, which is installed along the wall and down the staircase. The walls in the foreground are light grey and made of wood whereas the walls in the background are a darker grey and made of large stones with rounded edges.

right now, and I think that has always been the project of people who are disabled, because we live under ableism. Ableism is pervasive; it's still present and causing harm. The pandemic is clear evidence of this.

In various ways, disabled and non-disabled people have built a practice of care throughout the pandemic. But it's disability-lead mutual aid that has helped disabled people survive. Ten years ago, it might be rare to find ASL offered at an event, and if it was, it would likely be an unspecialized interpreter that the organizer may have found through their networks or online. Now, people are requesting interpreters that reflect their culture and experiences. And I think that shift towards personalized accessibility that is user-defined or community-defined allows us to set our own standards. This is really exciting because accessibility and these protocols that we have come to rely on, many of which are considered "best practices," were largely developed by non-disabled people and continue to define participation around a narrow set of guidelines. And now we're in a place of re-envisioning these systems around our demands and our desires.

I think our analysis is just getting stronger and advancing in this time of multiple crises, and maybe it has something to do with the fact that we are connecting with more people online, in intentionally held spaces that are dedicated to our community first. I think the way that disability justice, as a framework, provides guidance on how to create space that prioritizes BIPOC disability experiences is maybe the most important part of this.

Amanda: I'm excited about the future, though the pandemic has raised some interesting issues that many of us in the disability community are talking about. Everyone's asking me, "Do you think this is going to be helpful for disabled people in terms of online access?" I think it is helpful but also poses some serious questions, like, why wasn't this here to begin with? Why didn't people want to work with these online platforms to begin with for the benefit of disabled communities? Carmen: Right. The other thing that I think has changed, too, is that more artists understand their work as a form of accessibility. Accessibility as artistic medium. This comes up in Lisa Prentice's piece on Remote Access, the virtual live drag party series organized by Kevin Gotkin, Yo-Yo Lin, and friends. And I know that we've met a lot around this topic over the years and that it's a component of much of the work you've shown: artists that understand their work as accessible practice, whether they approach that through performance, installation, institutional critique, or whatever.

Amanda: Exactly. Carmen, you're one of the people that actually developed that as a solid practice, I think. Also, Christine Sun Kim, she's still doing that. You and Christine have always done that, and it's now becoming even more prevalent among other artists. There's an entire new generation of disabled artists that I'm starting to become familiar with doing the same thing.

Carmen: The knowledge that we've accumulated is a reflection of the resilience of our community. We've survived under ableism for so long, under medical systems that want to "alleviate the condition of disability" and erase our experiences, when we really just need to be supported in living on our terms. Disabled artists don't feel like they need to cater to a curator or an institution. It's more that we're looking for those supportive relationships with curators and other folks that can support our work and help advance our practices on our terms. Institutions are starting to understand that the checklist is insufficient, and it's not really about just adopting a protocol with no connection to a community. It's really about building meaningful relationships and trust with communities that have been excluded.

Amanda Cachia is an independent curator and critic from Sydney, Australia, who is based in San Diego, California. Her research focuses on modern and contemporary art; curatorial studies and activism; exhibition design and access; decolonizing the museum; and the politics of embodied disability language in visual culture.

Carmen Papalia is a nonvisual social practice artist with severe chronic and episodic pain. In 2021 he co-founded the Open Access Foundation for Arts & Culture (OAFAC), a pandemic-era cultural organization that aims to set a new cultural standard for accessibility by nurturing creative and justice-oriented accessibility practices. Addressing the limited representation of those with lived experience of disability in leadership roles within the visual and performing arts, OAFAC's activities advance disability culture and artistry within a contemporary art context through disability-lead trainings, curation, public engagements, exhibitions, performances, educational campaigns and site-specific project development with artists, curators and cultural workers.

Since 2009 Papalia has used organizing strategies and improvisation to address his access to public space, the art institution and visual culture. As a convener, he establishes welcoming spaces where disabled, sick and chronically ill people build capacity for care that they lack on account of governmental failure and medical ableism. His work, which takes forms ranging from collaborative performance to public intervention, is a response to the harms of the Medical Model of Disability, a framework that erases disability experience by reinforcing ableist concepts of normalcy. In 2020 Papalia was one of 25 artists who received the Sobey Art Award; in 2019 he was a Sobey long list recipient in the West Coast / Yukon region. Papalia also received the 2014 Adam Reynolds Memorial Bursary, which supported a 3-month residency at the Victoria & Albert Museum in London, and the 2013 Wynn Newhouse Award. His work has been featured at: The Museum of Modern Art, the Solomon R. Guggenheim museum, the Tate Liverpool, the Whitney Museum of American Art, the Banff Centre for Arts and Creativity and Gallery Gachet, among others.