On accessibility

Artist and activist Emily Barker on making art about inaccessibility, the need for real friendship and collaboration, why "normal" doesn't exist, caring for yourself and others, and rejecting toxic positivity.

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As told to Annie Bielski, 3028 words.

Tags: Art, Activism, Design, Process.

A major component of your recent show *Built To Scale* was a replica of your kitchen to the scale that would make it inaccessible for the average height able-bodied visitor. Will you talk about art, design, and accessibility?

The whole concept for the show came about because I'm very much a problem solver, due to the fact that being in a wheelchair forces you to be a problem solver. You have to problem-solve every single minute movement in space. It's such a dance. If there is an incline or a decline on the sidewalk, I can literally tip over in my chair, so I have to micromanage every single movement in space I make. When it comes to brushing my teeth, I can't reach my head over the sink and spit into the sink, and I'm often spitting onto the countertop because I can't make the reach.

I started thinking about ways that I could problem solve space for myself, and that was what I was initially going to make the show about, but then I realized able-bodied people have no idea what space is like for a disabled person, they just think you're in a wheelchair, you can't get up stairs, you need a big enough stall, maybe. Maybe they've thought that far. I was able-bodied and I didn't think about the fact that you have to pop a wheelie to get over the door ledge. When my friends try and use my wheelchair, they can't even leave my house, because they don't have the skills to get over the door ledge and out the door. In a way, the show was around explaining and showing, kind of forcing my perspective onto able-bodied people. A lot of people who came to the show were disabled, but can walk, and they were like, "Oh my god, I'm disabled, but I never thought space would be such a problem for you."

Some wheelchairs will lift people up so that they can reach things, but when I go into the grocery store, I can't reach a lot of stuff on the shelf. I can't reach a lot of stuff in my house. I just wanted to get that point across, that space for me, because it is built to the standard centering able-bodied people, is unusable, and makes my life quite difficult in a lot of ways, and makes my friends' lives who are in wheelchairs quite difficult as well. It forces you into this place of feeling like a child all over again. I wanted to give that same sort of experience, that infantilization, to the viewers in the show, so that they can understand a little bit better and try to fill in the blanks with some of the text pieces and the installation pieces.

Emily and collaborator Tomasz Jan Groza with *Untitled (Kitchen)*, 2019. Thermoformed PETG plastic cabinets, rivets, wooden base. Image courtesy the artist and Murmurs, Los Angeles. Photograph by Josh Schaedel.

My favorite piece is the room in which I played a looped recording of this classic hold-tune song called “Opus Number 1.” It’s played for nearly all hold tunes, whether you’re on hold for an hour waiting for an SSI operator to answer, or whether you’re on hold for Kaiser or Blue Cross to answer, this is usually the one that’s played. This room has this hold tune playing, and a stack of some of my medical documents that’s three and a half or four feet tall. I’m trying to paint this picture of: it’s not just inaccessibility, it’s also the fact that your entire amount of time in the day is controlled by bureaucracy and austerity, and health insurance companies, and fighting for your basic needs. Most of my time goes towards that, towards navigating something I would never think to navigate, and that my parents didn’t know how to navigate when my accident happened when I was 19 [and] forced to learn all of this.

Installation view featuring *Death by 7865 Paper Cuts* , 2019. Xeroxed medical bills and life-care plan from 2012-2015, 7865 sheets of paper. Image courtesy the artist and Murmurs, Los Angeles. Photograph by Josh Schaedel.

Being disabled and chronically ill, it’s not just dealing with an inaccessible world, you’re also dealing with systems that penalize you for something that’s out of your control that is happening to your body. On top of that, we live within a system that is ableist, and that is based off of the false eugenicist ideology of who has value, who doesn’t have value, and that penalizes you for being outside of the standards or the norms in which human beings are supposed to physically operate, when the reality is norms don’t exist. Norms are fake, normalcy is fake. There is no normal, and there should have never been the idea of normal in the first place, because no one has ever been normal. The body has never been standard. That is an idea that has propagandized people’s minds to being okay with the way in which the system fucks over other people that are not considered within the standards or norms that are societal constructs.

This idea of the individual and individual autonomy puts the responsibility back on the victim in every single situation and circumstance. I think space replicates that, I think objects replicate that, I think bureaucracy replicates these different systemic oppressive ideas. It’s pretty heavy, and I just wanted to give people the foundation of what my daily life was like, before I started working on ways in which solving it could be made very easily and affordably, which is the project that I’m working on now. It’s going to be where I live so that I don’t have to subject myself to the lack of social distancing, or my inaccessible overly-priced apartment.

Disabled people deserve to have accessibility, deserve to have their needs met, deserve to have healthcare, and that will only make able-bodied people’s lives easier, because [being able-bodied] is a temporary state. There is some point in someone’s life where they break an ankle, and they’re like, “Oh, this is awful, how does anyone deal with this?” and then [we] sadly do this thing where we push aside the reality that we’re all slowly dying, and that we’re all aging, and that we’re all going to get to a place where space does not work for us. We have so much cognitive dissonance to cope. We want to blame the person who the accident or the unfortunate event happens to, so that we don’t have to take responsibility for the way in which the world works or is shaped. As we can see with the protests happening, when people see a horrible amount of violence happening to people who in no way deserve that, and in fact deserve the entire world because of what they’ve experienced, we’ve seen how society often reacts to people standing up against systemic oppression and these norms, because we live in a country that is founded upon these ideas. Even though it is a horrible evil construct, that is America’s normal. I just want people to recognize that normal is oppressive, and the standards are oppressive, and that they actually inflict violence onto people, and violence is often a mundane bureaucratic thing that reinforces the pre-existing systems of power.

Grabber, 2019. Iron oxide on casted plaster. Image courtesy the artist and Murmurs, Los Angeles. Photograph by Josh Schaedel.

What's your relationship to collaboration and community?

I don't actually think that we currently have community, I think we have cliques. The support that I've received and the collaboration that I've had is often because there's a mutual vested interest in collaborating, or in helping with that experience, or it benefits the person helping. I think that we could do better to have actual community, but I think we've moved so far away towards this individualized harsh every-man-for-themselves kind of thing, that has forced us into figuring it out on our own, and not talking about the troubles that we face, because that is then considered complaining in our society. Is it community if my partner is helping me do stuff, or if a friend offers to collaborate on a project that mutually benefits them? I don't know. I have a core group of friends, but I would say I have been very disappointed by different spaces calling themselves the community, or calling themselves activist, or saying what their values are and then it's actually like there's no space for figuring it out, there's no space for meeting people's needs. It often feels more like Guy Debord's *Society of the Spectacle*. It seems like something that is just posted about on Instagram as an event for social or cultural capital.

Anytime I have engaged in a healthy, "Hey, I can't do this," or, "this made me feel this kind of way"—as soon as I am no longer helpful, abiding to these unspoken ableist constructs of how I should behave because I'm disabled, I'm discarded. I don't know if I believe in community in the US anymore, to be perfectly honest, and that's really sad. I think a lot of people feel very isolated. I don't know anyone that really feels like they have a super-strong community. That's not to say that I don't have an incredible amount of emotionally supportive friends, or friends who show up for me and help me with stuff when they can. I definitely do have that. Community is being born into a space that takes care of each other, and we've just moved way too far away from that. I think it's something that we used to have, and because we're so conflict averse and because we're so fragile, we make so many justifications for our implicit biases or cognitive dissonance on a daily basis. I think that there's too many things that would need to be necessary within all of us to actually have the kind of space available within ourselves to give each other community.

People don't have the skillset anymore to live and cohabitate the way that we used to, because we all need to learn transformative justice, conflict resolution, and all of that sort of thing, in order to live together. It's one thing to communicate, it’s another thing to listen and comprehend what someone else is saying and where they’re coming from. Two different people can experience the same thing, and have two totally different viewpoints on that thing, and everyone is coming from such different places that it just is hard.

Untitled (Ramp), 2019. Thermoformed PETG plastic, rivets, wood, broken wheelchair. Thermoformed PETG plastic cabinets, rivets, wooden base. Image courtesy the artist and Murmurs, Los Angeles. Photograph by Josh Schaedel.

I was recently reading about communes that intended to be progressive spaces, but instead reenacted various aspects of larger society they were attempting to move away from.

Yeah, I've had the same sort of oppressive ableist violence inflicted upon me in progressive leftist queer spaces, because people still don't know that basic accessibility should be a human right. I've been called aggressive for telling people that this is not okay. People would rather demonize other people than meet the needs that they're asking to be met. We have to be able to, in all instances, check our internalized misogyny, check our internalized ableism, check our internalized racism. We constantly have to be doing that work, but we also need to be making space for the mistakes that we're going to inevitably make when it comes to all of those things, because no one is morally superior. Where someone may have something down, they may have a ton of ableism, or they may have a ton of racism, a ton of misogyny, a ton of transphobia. To be able to navigate all of these different spaces we're going to have to have a little bit more patience for each other, is what I'm finding. No one is perfect, and we're not allowed to not be perfect now. That's going to require a lot of listening, and that's a skill that I don't have down yet. I don't think in a lot of America listening is valued, and I think we're going to have to learn how to listen.

Will you talk about the accessible artist residency/camp you are planning to start?

My long-term goals are to create an artist residency that would then sometimes be a camp for disabled kids. The cost of that would be millions of dollars, and I didn't really recognize that at first, so now I'm trying to start off with creating this mobile studio-slash-living space that's wheelchair accessible, that I hope to be able to turn into a residency when I'm no longer in crisis mode myself. I don't even have treatment for my CRPS, so I'm starting off with moving to a place where I'll be able to have a community garden, and I'll be able to hopefully do these sorts of things on a micro scale, and then I'm looking to move up to be organizing and running an artists' residency. I want to make sure whatever I build is only going to be used for people who have the same mobility difficulties in navigating space as me, because it's just a world of difference.

What have you been thinking about lately?

I've been thinking about this idea of sugar-coating everything. I think we all need to lean in to our teenage angst selves a little bit more. We're in a pandemic, and we're witnessing awful things daily that are reflections of what a sick place we've been living in, and I think that we all need to lean in to our ability to see the world for what it is, and not have to have things sugar-coated, and not have to have everything steeped in toxic positivity.

[I've been thinking about] being capable of doing enough self care and enough self love everyday in order to see and have the energy to make the changes in our daily lives that are necessary. [I'm] focusing a lot on the fact that a lot of us are experiencing poverty. How are we going to take care of each other, what are we doing to take care of the people around us, what are we doing to have healthy relationships around us, and to be open to receiving information that may not just be so feel-good? That's what we've been conditioned to be capable of receiving, unfortunately. That's a lot of the formatting of social media, it's either that or tragedy. I'm very self-aware on Instagram in that way. I realize what I'm doing in order to get attention, and to get people to read lengthy captions about stuff that might depress them, and I’m engaging in the spectacle in order to get visibility and to do advocacy work from my bed.

I think we would all be living in a much better space if we could develop better interpersonal skills with each other, and less tone-policing, less moralism, more patience—and I don’t mean with fucking rapists, and abusers, or millionaires or anything—but I just mean with the people you know next to you. I think people need to follow at least two disability-centered Instagrams. I don’t mean two influencers with disabilities, because that’s not the same thing. Visibility is not advocacy. I think being able to differentiate between the two is really important, because representation and visibility will never be advocacy on its own.

Art has been important and political art is very important, but I think all of us are very caught up in things that we think will make us feel good, when in the end of the day what actually made someone feel good was showing up for a friend, or being there for a loved one, or calling their grandmother, taking care of their grandmother, or doing something helpful. I think we need to change what our value system is. [Those are] overall ways in which I think we’ll be able to finally make the world more tolerable for all of us, before it incinerates itself.

Emily Barker Recommends:

Reading *The Disabilities Study Reader* by Lennard J. Davis, *Trapped in Americas Safety Net: One Family’s Struggle* by Andrea Louise Campbell, *One Straw Revolution: An Introduction to Natural Farming* by Masanobu Fukuoka, and *Health Justice Now: Single Payer and What Comes Next* by Timothy Faust.

Help those struggling close to you because you’ll learn how to better help yourself.

Learn about reversing deforestation and doing it to combat climate change.

Grow your own food and protest fascism, police violence, and white supremacy.

Practice patience, kindness and boundaries. Don’t eat foods that cause depression.

Name
Emily Barker

Vocation
Artist, activist

Courtesy of Emily Barker Alt text: Emily, a white person with red hair, wearing a black turtleneck