Activated: Decentering Activism in and with Academia

Franchesca Spektor
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I'm an ambiguously ethnic, light-dependent, and working-class designer who works with disability communities, sex workers, and most recently unionized housekeepers. I've spent the bulk of my childhood trying to keep the people I love from hurting. Now, in my career, I find myself working to keep people I have little relationship to from hurting. I want to understand why I do this work, and critically explore the ethics of representing* voices of groups to which I don't always belong. In particular, I want to examine this as a (very new) researcher who is now part of an institution — a domain of relative power. What are the ethics of doing "ethics work"? These few raw excerpts are my ongoing reflection of this journey — a journey I would be grateful to share with community through this workshop.

*While "representation" is neither my role nor inclination in participatory work, my compensation as a researcher seems dependent on how well I can represent my co-conspirators' values as *meaningful* to the field of HCI.

WHY DO THE WORK

As I came into my PhD program in the fall of 2020, I wanted to understand how technological systems and market forces construct socially valuable bodies. In particular, I was interested in what such values mean for non-normative bodies that are instead violently transformed or erased. Before 2020, this work had led me into a number of activism spaces that looked like cozy-cramped living rooms, dance halls, and late nights in my makerspace. Now that this work leads me to HCI conferences and GoogleDocs, I ask myself why I want to "study" this so much.

I often tell the story about my first interview for a project on assistive technologies with Corbett OToole, a queer disabled elder and disabiltiy rights activist from Berkeley, CA. I'd sat down with OToole to ask her stupid questions, like "Are you excited by the development of exoskeleton technology?" She said, "I don't give a shit about exoskeletons, if I can't even get a robust health plan." Assistive technologies of the future are created for normative bodies, OToole explained. Even exoskeletons, she continued, are made within a height and weight range exclusive of many disabled people. After all, technologically enhanced bodies assume a baseline at which disability no longer exists. I walked out of that interview with a new brain.

The people that look forward to exoskeletons: people who invest in and develop them, people who can afford them, people who could physically wear them. And everyone else? Poor bodies, BIPOC bodies, disabled bodies, fat bodies, queer bodies — at best, they get left out of the conversation. At worst, exoskeletons are designed to “fix” or eliminate them. I see the people that look forward to exoskeleton technology at HCI conferences. We write GoogleDocs together, which feels like progress, but I’m no longer sure for whom the knowledge we produce is for.

Is it the best we can do, to accurately collect and document rage, and let other academics look at it in hopes they too are convinced? The problem with academic activism work is that it places injustice under the scientific method — something to be researched, fetishized, and dissected by people who may never have to truly feel it.**

**This is the same model used by powerful institutions who consistently lack the data to act (e.g. the New York City Department of Education running the same “diversity research” initiatives since the 1950’s on segregated schooling).

WHO BENEFITS FROM THE WORK

Charity models often depend on the sustained oppression of a group. Even in the worst of scenarios, it’s hard to hold such institutional power accountable to public perception: Shaun King continuing to profit off of Black pain despite multiple callouts, content about Autism Speaks coming with a trigger warning in neurodivergent circles. How do academics doing activism work profit from the work we do? Do we get paid? Do we get social status? Do we get to build our career off others’ pain? In my case, the answer to some of these questions is yes. I have built a PhD research program on “fixing a problem” that is not directly “my problem” but affects me in ways I find important. There are lots of other people in academia who work on issues that affect their own communities and don’t profit nearly as much. If and when they do, it may come at great emotional cost, including the uncomfortable blurring of personal and professional boundaries. I would like to spend more time understanding both the profit allotted to and payment extracted from researchers in this way.

How does research profit the people we’re working with? None of the communities I’ve ever done projects with have read the papers that resulted from that work — the metric of my own success as a researcher. I probably wouldn’t have read them either, since there would be nothing new to learn. I’ve committed instead to a compromise: I only do community projects that have been requested. In other words, *I try to build the kinds of relationships where people can tell me what they need and want, and then we get to work*. The problem with this approach is that the resulting work is often entirely *unpublishable*. For example, I attempted to start a research project with a team of blind sex educators to build tactile sex education models. The research itself quickly fell apart because members had concerns over their treatment in previous instances of academic collaboration. Yet, the team has since grown to over 12+ regular members who meet multiple times a week. We conduct interviews, write guidelines, and make models — all beyond the boundaries of academia.

As a roundabout to this issue, I’m looking for literature that speaks explicitly to how to start doing ethical accessibility or assistive research as a non-disabled person. While there is certainly academic work that focuses on agency and community involvement, I've also come across thought articles written by disabled people who must consistently educate "well-meaning" researchers and engineering students — or are otherwise harmed by violent research practices (most recently this r/blind reddit thread and this older post by Josh Miele).

Looking over troubling assistive tech-related proposals from my cohort these last few months, I wish there was more "legitimate" literature I could send their way. Despite the volume of plain language online content (produced by people with disabilities), it seems like much of it doesn't fully penetrate our field. Accounts like Miele’s reveal clear accounts of harm; there are far fewer accounts of the benefits received from research.

WHAT PROGRESS LOOKS LIKE — ENDLESS QUESTIONS

It seems to me that when we do this kind of work right, what’s revealed, for the most part, is: you can’t fix this alone. The problems we contend with are so much larger than an app or a technological system, even as our metrics of value rely on making things and solving problems. There’s almost nothing to do against poverty, lacking infrastructure, and social bias on the level of HCI. What does your ego do with that?

Maybe part of the answer is creating new structures of value around activist-scholarship. Technological venues could include specific tracks on how existing technologies would be implemented and how much they would cost, describing the repair and maintenance of technology, and collecting ways in which non-technological tools work better for people. I have often run up against these as “illegitimate” contributions, because research is meant to be aspirational. Perhaps I aspire to small, pragmatic interventions.

One of the other questions I’m deeply interested in exploring is: who are we talking to when we write about activism-related work? Instead of (in addition to?) publishing academic papers, we can consider avenues for disseminating information that are more accommodating toward warm, soft, public-facing data. If and when we do talk to our peers, how can we do so in a way that’s reflexive, rather than describing a problem that’s “over there”? Most importantly, I think about what a paper that my community partners would want to read actually looks like. I imagine that rather than describing what’s wrong and how someone else should fix it (like many papers I’ve written), it would be a receipt of real change.

Finally, I would like to continue discussing how we as researchers can be better collaborators. In technical terms, I want to talk about what it would mean to overhaul the IRB structure to allow for easier data sharing with community partners, or how to compensate people as liaisons and not simply participants. I’ve experienced academia’s grain as deeply discouraging from the kind of relationships I’d like to build: to hire people as experts, to send handwritten thank you cards, to contribute materially to their education, etc. I hope that through conversation and community, we can start to do this work better.