



Dispatch

“Giving Voice” in Research: Critical Community Reflections

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This dispatch reflects a series of short back-and-forth dialogues between a postdoctoral researcher, an executive director, and a program coordinator working toward a community-based research project for social justice at the University of Regina. Through snapshots of our weekly discussions from January to November 2019, we grapple with transforming community-based programming into research, and the potentially unresolvable structural inequalities at work in the research-based studio space known as the Vocally Oriented Investigations for Communicative Expression (VOICE) Lab. The purpose of this space, established in 2018, is to make room for youth with complex disabilities to explore arts-based storytelling using digital technology that usurps rehabilitative and therapeutic ideals of “giving voice.” Our job was to turn this storytelling activity into research. Here, we draw on snippets of conversations to show readers some tensions around formalizing our community programming into academic research. We each move away from an unfinished project carrying fears about who is – and is not – listening to the people with disabilities involved in this research, and we make recommendations on what is needed for other academic and community hybrid groups embarking on lab-based community projects.

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Introduction: Setting the Scene

A campus coffee shop, morning. Three white working-age women sit at a square table, tea or coffee in hand. This is our regular, weekly meeting space. Two of us staff the Big Sky Centre for Learning and Being Astonished! Inc., – better known here as Astonished! – and we regularly squeeze into a small office space stuffed with papers, baskets, markers, and other miscellaneous fundraising and program supplies.

On one side of the table is Bonnie Cummings-Vickaryous, the Executive Director of Astonished!, a charity that draws on the expertise and knowledge of young adults with complex physical disabilities “to build inclusive communities based on their strengths, dreams, and needs” – as is the group’s often-repeated mandate. Cummings-Vickaryous is part of a four-person research team that, in 2018, established a new space on campus called the Vocally Oriented Investigations for Communicative Expression Lab – better known as the VOICE studio. She oversees the programming for the seven disabled people who make up Astonished!’s “core members.”

Also at the table is Katherine Taylor. As Astonished!’s Program Coordinator, Taylor knows the core members intimately. Her engagement with these people, who are potential research participants, is crucial to the social justice work at hand, for Katherine can communicate with those who do not communicate verbally. Many core members communicate with eye movements, sounds, and smiles.

Finally, the third person at the table is Chelsea Jones, the postdoctoral researcher who has been getting to know Bonnie, Katherine, and all of the core members over the past year.

January 2019: Is Research Desired or Obligatory?

It’s mid-winter, and the VOICE Lab has just opened. Astonished! core members are slowly settling into a routine that involves weekly studio time with Chelsea where they make podcasts, soundscapes, and play around with recording gear and iPad apps. Unfortunately, the VOICE Lab is inaccessible by design – it was built with narrow door frames that are a tight squeeze for core members, who all use wheelchairs. Only one person can fit into the studio at a time, so the core members have opted for individual creative projects rather than group-gearred storytelling.

Chelsea (postdoctoral research fellow): Alright, so, our goal so far has been to acquaint folks with the technologies in the VOICE Lab – iPads, a looper, desktop computers, microphones, and speakers – so that they can get a feel for arts-based research without having to commit to being part of a research project. But now we’ve gotta hatch a research project.

Bonnie (Astonished! Executive Director): Yeah, we do. We, as a community based organization (CBO), have a memorandum of understanding with the U of R that says we must work with the university to develop research opportunities, and to create opportunities for students and faculty to work with people with disabilities.

Chelsea: So, you already have a pre-ordained agreement with the university that core members will be involved in research from time to time, if they're up for it?

Bonnie: Yes. And our funders expect that we *will* do research. Programming, as we've done so far, isn't enough to satisfy the funders.

Chelsea: How do core members feel about that? Is engaging in research what they want?

Katherine (Astonished! Program coordinator): We know that some members of our community will be interested in research, others not. But I expect that they'll be more open to research ideas coming from you, Chelsea, because you've been at "coffee time" for the past several months.

February 2019: Laying Foundations for Research at "Coffee Time"

In the early days of our programming, we found that rather than thinking in terms of how the community might get involved with the VOICE Lab, one of the first things we had to figure out was how Chelsea – as an outsider researcher – might get involved with the community. The most straightforward path toward the community was via regular "coffee time" hang outs. Coffee time takes place regularly at a plain campus food court, where core members bring packaged snacks and to-go drinks to an hour of conversation around a table lit by overhead florescent lights.

This "hanging out" was a method of immersing oneself as an outsider in a social experience on an informal level (Walmsley, 2018, p. 277). For Chelsea, this immersion felt like participant observation and lasted for about five months. She spent coffee time learning people's names and learning how to communicate with people who do not speak verbally (Pfaelzer, 2010). Though Chelsea was welcomed in many ways, she was also being tested – people asked about the VOICE Lab, about her research question, and about her purpose (Jones, 2019).

Chelsea: Okay, so one of the biggest take-aways I have from spending coffee time with folks is that sometimes core members' experiences with research kind of suck.

Bonnie: Yeah, I know. That's why we made sure you, as a researcher, spent time with people before beginning research was a good idea.

Katherine: Eventually we can begin inviting people to the VOICE Lab for research, not just for fun. These invitations will rely on the trust-building that took place during coffee times. Rebecca Caine and her fellow researchers (2016) reminds us: “each project has a life of its own that is often unpredictable” (p. 35) – and this has proven true. It’s much easier to handle unpredictability when there’s trust already built into what we’re doing.

Chelsea: It’s clear that I’m an outsider to this world. Even though I have a background in critical disability studies, nobody else shares that perspective. Stepping away from the books for a while and just sitting, listening, and responding to questions helps. It doesn’t make me an insider, but at least I’m not a stranger.

Katherine: People trust you. This is good for the university because it means folks are more likely to buy into whatever research you pitch.

Chelsea: Sure, but the purpose of research should never be buy-in for the sake of buy-in – that would be a shitty violation of any trust that’s been built.

Bonnie: Moving forward, we need to design a research approach that’s actually worthwhile for core members.

Break from Discussion: “More Conversation, Less Inspiration”

Here, we take a break from the dialogue between the Astonished! Executive Director, Program Coordinator, and the post-doctoral researcher to showcase an emergent example of VOICE Lab work. Below is a transcript of an excerpt of core member Kelsey Culbert’s podcast, “Less Inspiration, More Conversation.” Here, Culbert tells a story about self-identity. The episode goes on to discuss how, if people would just listen to her, it would make everyday things like getting coffee more accessible. Kelsey shares the recordings on Facebook to solicit feedback from her community.

[Podcast Transcription]

Chelsea: So Kelsey, what’s new?

Kelsey: I’d like to start off by telling a story about a research interview I had just last week. The interview was about resiliency and how society views me as a person. However the [interviewer] was very nervous and felt a lot of pity on me. Me being the interviewee was like, was like, what are you so nervous about? Because the interviewer kept saying, ‘Oh my god I feel so bad for you, I feel so bad for you.’ Like, I mean, what is there to feel bad about? Really?

Chelsea: Let me get this straight. You were being interviewed by someone who wanted to research resilience, and they kept saying that they feel bad for you?

Kelsey: I, I'm really not interested in your pity, and I really don't need help. Because his follow-up question was, 'Can you drink by yourself?' and my response was, 'Yeah, I sure can.' And I took another sip and he became more nervous.

March 2019: Becoming Entangled in Institutional Agreements

In 2017, the Astonished! Board of Directors reached an agreement with the research team: if Astonished! was to be the community-based organization named in grant applications about the VOICE Lab, the VOICE Lab would provide core members an opportunity to create arts-based projects. In part, this agreement was made on the premise that community-based arts research projects present opportunities for artistic expression and descriptions of place or environment, as photovoice and digital storytelling projects have demonstrated many times over (Dassah et al., 2017; Povee et al., 2014; Rice et al., 2015). Here, we return to that agreement and try to imagine what core members' creative activities can look like when they become research activities entangled in institutional agreements.

Bonnie: It's been months, and we're still asking: how will this research serve core members?

Chelsea: Well, we might think about whether or not the groundwork we've done so far has served the community. For instance, there are two podcasts in production in the VOICE lab. Do these things serve the community?

Bonnie: Yeah, the podcasts serve us because they provide a meaningful opportunity for those who are interested in creating arts-based projects as part of their programming. But we can take this further. We can research how the VOICE Lab serves some people and not others. For example, none of the core members can access the VOICE Lab without a key or without someone to operate the technology. So, the place is only usable to disabled community members when a researcher is there.

Katherine: Why do we have to do research at all? The VOICE Lab already serves the Astonished! community without a research component. The same way that our weekly yoga sessions serve everyone, but nobody's researching it! In some ways that's the nice thing about the VOICE Lab – that nobody has had to do their creative work under a research gaze...

Bonnie: From our perspective, the sole purpose of the VOICE LAB shouldn't be research – but it is. We need to do research to secure our funding.

Chelsea: One thing we need to think about is that we can't continue doing all of this in our regular programming without the VOICE Lab being staffed. I mean, we can't assume that someone can just roll up to the VOICE Lab and make a podcast or build a song on their own. Astonished! staff do not have the

technological expertise required to support the Astonished! core members. And because the space isn't accessible, we aren't properly set up to continue the programming.

May 2019: “More Conversation, Less Inspiration”

In the months following the VOICE Lab's opening, several projects emerged: podcasts, mixtapes, soundscapes, ink art, video documentaries, and other expressive forms of communication. We attempted to work on the premise that community-based arts research helps people convey thoughts and feelings in a more accessible way (Richards et al., 2019, p. 207). Our hope was that our research can do something similar, with a critical focus on audio-based creative expression as a method for resisting ableist tropes around “voice” and “giving voice” (Alper, 2017).

Chelsea: Okay, so, here's the research question I keep coming back to: ‘What does “voice” mean in the context of a burgeoning, but underrepresented, disability art and activism movement on the Canadian prairies?’ This is an interesting question to ask in a problematic space like the VOICE Lab. The space got this name before any of us arrived, and it's a somewhat ironic name because many of the people working there are not using vocal modes of expression – such as talking – as a primary mode of communication.

Katherine: Still, some people are talking as they make their creative projects. Think of Kelsey's podcast, for example. Can we fold this into the research somehow?

Bonnie: Sure. The plans for how these projects unfold are intentionally very flexible – we want to make sure there's lots of space for folks to experiment, change their minds... and just be involved in the iterative process of content creation at their own pace.

May 2019: Competing Research Goals

Five months following the VOICE lab launch, we realized that the community based organization (CBO) and the university had different goals for the research. Astonished!'s goals are to: (a) expand access to and build opportunities for young adults with complex physical disAbilities to engage in meaningful arts-related activities according to their strengths, dreams, and needs; (b) increase knowledge on assistive technology, software and adapted equipment needed to fully support adults with complex physical “disAbilities” to be active artists; and, (c) cultivate cross-disciplinary learning skills and attitudes with collaborating partners and volunteers

Meanwhile, part of the purpose of the VOICE lab, from the university's perspective, is to: (a) make space for and support people who are not

professional artists in making art/engaging in creative/crip work in ways of their choice; (b) provide opportunities for community engagement in research; and (c) mobilize regional academic and non-academic audiences with the potential to impact disability communities, researchers, and policy makers concerned with the ways in which disability art and its production are represented locally and nationally.

With these realizations at hand, our conversations began to focus on how to reconcile these competing research goals.

Bonnie: We need to think about ways to grapple with the competing expectations of the research and the expectations of the CBO. We have to curb our practice and think about how what we're doing can be research that is oriented toward core member's strengths, dreams, and needs.

Chelsea: I think we also need to pause and consider what it means for researchers and community members to be accountable to one another's work in the iterative, co-constructed process of community based arts research at its emergent stages. This is a co-learning process – one that has to emerge over time.

Bonnie: Yeah, but if our goal is to work toward research that meets core member's needs, we need to focus our activities around our core members' strengths, dreams, and needs. All of Astonished!'s work is grounded in the strengths perspective, which puts a focus on "what people want their lives to be like, and what resources and strengths they have or need to get there" (Saleebey, 2009, p. 12).

Chelsea: Okay, but even if both the CBO and the university can find some common ground by focusing on participants' strengths, dreams, and needs, the methodology may be contentious. But, epistemologically, I think we're coming from the same place: following the work of Meryl Alper (2017), who ties communication technology to digital equity and reminds us that voice "is an overused and imprecise metaphor – one that abstracts, obscures, and oversimplifies the human experience of disability" (p. 5).

Katherine: So, we can try to make clear from the get-go that we are not in the business of "giving voice."

Chelsea: And, to keep the work critical, we need to tease out the ways in which questions of "voice" and disability crop up at the intersections of class, race, and rurality among others. We also need to uphold "voice" as politically significant. Indigenous, critical race, and feminist scholars have cautioned against "giving voice" for some time. It also matters that we're white and non-disabled, and that most of the core members participating are white. We're operating in a very white-washed space.

June 2019: Anticipated Challenges

In June 2019 Katherine and Chelsea are preparing to present on the VOICE Lab research at the Canadian Disability Studies Association/Association Canadienne d'études sur le handicap annual conference. We gathered notes from our conversations, with the intention to talk about the process behind the emergent research. Our conversations are rife with competing themes: the inaccessibility of the space goes against core principles of disability arts, yet core members are resiliently producing creative content; relationships have been established through coffee time, but these relationships somehow seem at odds with the entanglement of institutional agreements we find ourselves bound within; and, Astonished!'s goals and the university's goals still do not fully align.

Other challenges are more straightforward, and we present these to our audience: overlapping features that must inform our future methodology in an ongoing way are crip time, access, and diversity. Below is part of the conversation leading up to the presentation.

Bonnie: This research is taking a long time. We need to tell the audience this.

Katherine: It takes so long! It's been months and we are still talking about research rather than really doing it.

Chelsea: Some of the delay is around crip time. We need to make extra time for people to account for things like accessible transportation and equipment malfunctions (Kafer, 2013). We also need to account for waiting. This might mean waiting on the university to download an app we need for the iPad or waiting for decisions around grant funding for required technology or waiting for someone to let us into the studio –

Bonnie: – and without automated door openers, core members need to *wait* for another person to open the doors so they can enter the space.

Chelsea: We can also point out to a national audience that on the prairies, access exists at the intersections of race, class, and rurality, pointing to the importance of place in our incipient understandings and articulations of disability art here. I mean, sometimes it's just too damn cold for anyone to make it into the studio, especially if it means waiting for a bus.

Katherine: Also, the studio is still not accessible, and there's no indication that it ever will be – there's no budget line for access. So, if people want to engage in research in a collaborative way, and make decisions as a group, that's hard. It's important to note that we are expected to *do* community-based research, but we are not working in a space designed to include everyone.

Chelsea: While we're at it, there is no BIPOC representation in this research. Because we are beginning this project with people who are already on campus and working with Astonished!, there has not yet been an opportunity to recruit

additional folks. Even if we reach a moment where we have time for this kind of recruitment, what can we offer BIPOC folks? That's a rhetorical question, because I suspect the answer may be, "nothing." The space was seemingly not built with BIPOC folks in mind, and it will be difficult to recruit without tokenizing them.

Katherine: We also face some clear challenges around collaboration and communication. For many people using the studio, part of accessing the studio means keeping your community in the loop. For example, people can also take technology out of the studio. Often when people take technology home there's a learning curve – someone might take a voice recorder or an iPad – and families are left wondering what to do with this stuff.

November 2019: Recommendations

As we grapple with unresolved methodological problems related to crip time, access, expectations around technology and other challenges, we are left wondering how, exactly, we ought to move forward. Crucial to the future research planning is the question of presence. It has taken so long to get the research off the ground in inaccessible conditions that our respective time with the core members is coming to an end. In the months leading to this conversation, each woman made an announcement: Bonnie told us about her plans for maternity leave; Katherine was accepted to nursing school and said goodbye to core members; and Chelsea found another job in a different province.

We move away from this truncated project with little resolution. We have fears about who will complete this research when we step away, and if the participants we've come to know over time will have a say in what happens going forward. In an effort to offer some closing remarks, below is one of our last conversations as a group, which focuses on recommendations for future research of this type. That is, research that involves disabled folks with complex physical disabilities for whom speaking is not always the most effective way to communicate, the university, and a CBO.

Bonnie: My recommendation is: "go for it," even though it's complicated. The benefits outweigh the troubles. Doing a project still helps people get a taste of art, so they can go into the community in different ways.

Katherine: I agree, and if we can add to the literature by doing that, then great. If not, that's okay too.

Bonnie: Research can help with the larger mission of building inclusive communities, but it is clear that these projects rely on an interdependent approach to research. One lesson we are learning is that we have to collaborate on communication plans for each person's community, so everyone involved in supporting the artistic creation.

Chelsea: I would recommend making sure access is built into the planning of this type of research. A lab space for disabled people isn't really for disabled people if access isn't part of the planning. I think it's okay that the research moved slowly – after all, we value crip time (Kafer, 2013) – but there was a lot we couldn't do simply because the physical space was not accessible, and because BIPOC people were not invited to participate. Those would be my recommendations for other folks: make the space accessible from the get-go.

References

- Alper, M. (2017). *Giving voice: Mobile communication, disability, and inequality*. MIT Press.
- Caine, V., Mill, J., Jackson, R., & Masching, R. (2016). *Essentials of community-based research*. Left Coast Press.
- Dassah, E., Aldersey, H. M., & Norman, K. E. (2017). Photovoice and persons with physical disabilities: A scoping review of the literature. *Qualitative Health Research*, 27(9), 1412-1422.
- Jones, C. (2019). That time I punched a boy in the forehead: Sibling stories ahead of research. *Disability & Society*, 34(4), 657-662.
- Kafer, A. (2013). *Feminist, queer, crip*. Indiana University Press.
- Pfaelzar, J. (2010). Hanging out: A research methodology. *Legacy: A Journal of American Women Writers*, 27(1), 140-159.
- Povee, K., Bishop, B. J., & Roberts, L. D. (2014). The use of photovoice with people with intellectual disabilities: Reflections, challenges and opportunities. *Disability & Society*, 29(6), 893-907.
- Rice, C., Chandler, E., Harrison, E., Liddiard, K., & Ferrari, M. (2015). Project ReVision: Disability at the edges of representation. *Disability & Society*, 30(4), 513.
- Richards, M., Lawthom, R., & Runswick-Cole, K. (2019). Community-based arts research for people with learning disabilities: Challenging misconceptions about learning disabilities. *Disability & Society*, 34(2), 204-227.
- Saleebey, D. (2009). *The strengths based perspective in social work practice*. Allyn & Bacon.
- Walmsley, B. (2018). Deep hanging out in the arts: an anthropological approach to capturing cultural value. *International Journal of Cultural Policy*, 24(2), 272-291.