Imagining and Accessing Lived Realities in Research Interviews

By
Stephanie L. Kerschbaum

Paper presented at the Society for Disability Studies Conference
Orlando, FL
27 June 2013

Contact Information
Assistant Professor, Department of English
Faculty Scholar, Center for the Study of Diversity
220 Memorial Hall
Newark, DE 19716
kersch@udel.edu
http://sites.udel.edu/kersch
In this presentation, I report on the design of an interview study I am co-conducting with Margaret Price. This interview study aims to more fully understand and explore a currently under-recognized and deeply complex phenomenon: the ways that faculty members with disabilities disclose their disabilities in everyday life and work.

In putting together this study, a central concern motivating our study design and implementation is this: how can our methods enable us to “access the lived realities of disability disclosure?” Here, access both refers to our need to better understand this phenomenon and gather stories and experiences for analysis as well as to participants’ need to access our data generation methods. Research is accessible not only to the degree that the researchers can gain entrée to a situation, but to the degree that all participants involved—researcher, interview participant, interpreter, personal care assistant, whoever—are part of the research enterprise. Margaret has already talked about how this means moving away from “objectivist” or “gold standards” for research in order to engage in messier “scenes” of research and communication.

In the discussion that follows, I’m going to talk a little bit about how we are approaching the study of disability disclosure, zeroing in on two of our research questions:

1. When, how, and why do faculty members decide to disclose, or not disclose, their disabilities at the workplace?
2. For those who choose to disclose, what is the experience of disclosure like?

There are a variety of means to study faculty members’ disability disclosures.

One way is to document moments of disclosure, as one might do in an ethnographic study following one or more faculty members as they go about their work lives, documenting disclosures they perform along the way. I have begun an autoethnographic version of this project in examining the many contexts and moments in which I call attention to my own disability in the course of going about my everyday work as a faculty member.

As valuable as my own experiences are to my theorizing, I needed to move beyond my own experience to understand disability disclosure across a broad spectrum. The first move I made was to turn to scenes of disclosure within disability memoir and disability studies scholarship (Kerschbaum “Rhetorical Agency”). In the course of this work, I came to realize ways that these written disclosures functioned very differently from other kinds of disclosures, and I began to think about moments that might not be captured in the memoirs and scholarly essays I was reading. So when Margaret and I joined together to design our interview study, we both thought carefully about how we could access all kinds of disclosures, occurring in all kinds of academic settings.

The approach we are taking in this project is to interview faculty members to solicit narratives of faculty members’ experiences disclosing their disabilities, asking them to describe the variety of

This is a work in progress also available on my website, sites.udel.edu/kersch/presentations.
You can cite it as a conference presentation.
contexts, situations, and audiences to whom they have disclosed or with whom they have addressed their disability at work.

Our aim in these interviews is to solicit narratives of disclosure, stories about times when faculty members have disclosed their disability in some way—or had it disclosed for them.

[SLIDE: Outline of talk] In the remainder of this presentation:

1. I first discuss the narrative framework we are developing for analyzing narratives of disability disclosure.
2. Within this framework, I’ll highlight how the participatory structure of “marking difference” has promise for enabling researchers to “access” disclosure narratives,
3. And I’ll conclude by identifying some limitations of narrative analysis for accessing the lived experiences of disability and disclosure.

Narrative Framework for Analyzing Stories of Disability Disclosure

Let me talk a bit here about my work analyzing written stories of disability disclosure, in which people write about times when they have disclosed their disability to others. I’ll then point out how these stories—whether they are written or told during an interview—differ from lived experiences of disclosing disability. This difference highlights some of the limitations of accessing disability disclosures through narrative structures.

[SLIDE: showing an image of the front cover of Kleege’s book] In the first chapter of *Sight Unseen*, Georgina Kleege details some ways that she navigates others’ perceptions of her blindness and claims her blindness in specific, strategic ways. In writing about these stories, I used them to help me think through my own experiences negotiating disability disclosure in academic writing. Through this work, I came to realize the variety of ways in which I have disclosed—differently—to different audiences, in different contexts, and at different times, over the course of my academic career.

At this point, I got acutely interested in the ways that such disclosures might operate through narratives of disclosure, such as the one Kleege tells. There is, after all, a difference between a story about a past event in which a disclosure happened, and the in-the-moment, future-oriented act of disclosure itself. That is, there’s a difference between writing, “I am deaf”—as I have done in several publications now—and telling a story about how people have responded to a disclosure (even if telling the story is also a means for disclosing, as regularly happens in disability research).

The distinction I am pointing to is this: when Kleege and I tell stories about how we disclose in typical settings, we provide access to conscious actions and states of mind that are not always evident to selves or to others during performances of disclosure (see also Wilkerson; creating selves through narrative). More significantly, these stories represent engagement with actual—not imagined—audiences, and when people tell these stories of disclosure, they often already know how those encounters have turned out, or how audiences have responded to them—or they can portray those audience reactions in very particular ways. Narrative forms allow us to show our choices as purposeful and as embued with particular moral significance (see Johnson; Ochs

This is a work in progress also available on my website, sites.udel.edu/kersch/presentations.

You can cite it as a conference presentation.
and Capps), and in this way they are an important means of exercising rhetorical agency when it comes to disability disclosure.

In contrast to narratives of disclosure, however, lived experiences, and my own decisions about whether or not to disclose my disability in my own academic writing have been largely characterized by uncertainty about how others might respond and they represent an engagement with imagined, rather than actual, audiences. And, because I’m the one who has written my own disclosures, I am acutely aware of the minute decision-making going on behind those disclosures, trying to parse apart whether to mention, how to mention, or when to mention my deafness in any given text, but I don’t have similar access to others’ decision-making in their writing.

Thus, questions about accessing moments of disclosure through narrative must necessarily take up the context in which the narratives are shared (e.g., a research interview aimed at better-understanding disability disclosure) as well as the temporal orientation of these narratives: do they represent completed events, imbued with moral significance or are they messy, ongoing, and unclear? What kinds of narratives unfold as interview participants talk about their experiences disclosing—or not disclosing—disabilities at work?

**Participatory Structures for Accessing Lived Experiences**
I’ll turn here to address in more specific detail the interview study that Margaret and I are conducting ([more information about that study can be found on my website](http://sites.udel.edu/kersch/faculty-with-disabilities-in-higher-education-interview-study/)). We have asked each of our interview volunteers to let us know what interview modalities they would be comfortable with, [SLIDE: showing list of interview modalities] including in-person, telephone, Voice over Internet Protocol (e.g., Skype or FaceTime), email, internet messaging, or some other format. In thinking about how to conduct interviews across these different modalities, we have also thought carefully about our own comfort levels as interviewers. For example, while I can do phone calls with an interpreter, I strongly prefer not to, and I am very comfortable using internet chat programs but recognize that many people are not as familiar with them or as comfortable with them as I am.

These different modalities present interesting questions for us as researchers. Asking participants to choose modalities they are comfortable with is important to us as a means of enabling effective communication and for allowing participants to construct and display the selves they want to display during the interview, but it does present some complexities in terms of how to conduct the interviews.

Interviews are already unique social situations that many people don’t experience regularly, so they can be awkward to negotiate even if they happen in a familiar modality. Many texts on conducting research interviews spend considerable time on “how to do” an interview, for the very reason that new interviewers need to understand how an interview context differs from other kinds of interaction, with the aim of demystifying some of the expectations for behavior in these contexts.

This is a work in progress also available on my website, sites.udel.edu/kersch/presentations. You can cite it as a conference presentation.
Let me give an example. In *Interviewing as Qualitative Research*, Irving Seidman explains that while an everyday conversation might involve a great deal of back-and-forth, with both participants contributing equally to the discourse that unfolds, in an interview context, interviewers typically want to allow participants to do most of the talking, and interviewers will typically not share their own experiences in response to something an interviewee says. In this way, even if an interview might sometimes feel like “a conversation” (a metaphor that is frequently invoked to describe successful interviews), it is nevertheless a particular kind of conversation, constructed in a very specific way.

During an interview, then, interviewers display specific cues signaling that interview frame in order to orient their interviewees to that context. This can be tricky when interviewees are people that interviewers know well. For example, Margaret and I are currently conducting pilot interviews for our research study, and we’ve contacted a small sample of interview participants. In communicating with one participant, Margaret used the phrase “I’m putting on my researcher hat” as a way of signaling that she wanted to distinguish the interview/research context from a more personal interactional context.

[SLIDE: Marking Difference] Such signaling is part of a system of cueing positions and identities—what I call “marking difference” (Kerschbaum “Avoiding”)—that is an element of all forms of communicating. Marking difference uncovers how individuals craft themselves in response to perceived differences that they interpret from others’ bodies and interactional performances. Marking difference is important to designing and implementing accessible research because it highlights several key elements of communicative situations that matter to how interviews might unfold:

- Participants’ positions are not static throughout an interaction—interviewers and interviewees can conceptualize their roles differently, and the continued performance of any role depends on support and participation for that role from other interlocutors.
- Different elements of a communicative context can become relevant at different times or be invoked differently throughout an interview.
- Communication is not “natural” but co-constructed in varying ways across many different interactions.

What this means, then, is that when the interviews take place in modalities the interviewer and interviewee are less familiar with, it is important to think about the different affordances across these modalities in thinking about how to conduct, record, transcribe, and analyze the resulting data (see Price, “Disability Studies Methodology”). That is, it means thinking about the different ways that people mark themselves and others during an interview.

To talk in more depth about this, let me offer an extended example in which I describe how different interview contexts have an impact on how I might cue these positions and negotiate different means of communication. I engage others in “conversation” in myriad ways on a daily basis. Some of these ways include [SLIDE: Everyday communication modalities]

- in-person spoken discourse
- using sign language in person
- phone calls using an in-person interpreter

This is a work in progress also available on my website, sites.udel.edu/kersch/presentations. You can cite it as a conference presentation.
I have my own preferences as to what works best for me, and where I feel most comfortable, most like “me.” My aim in conducting interviews is for interviewees to feel comfortable, as if they can communicate in a way that allows them to present themselves the way they want to be understood and interpreted by others. But as I think about my varied means of communicating, and the reasons for which I choose some and not others, I’m also aware of the differences among each of them, differences that are important for understanding how I mark difference and respond to my interlocutors’ markers of difference.

Let me elaborate. In person I have a number of cues I use, using both body language and verbal utterances, to mark difference and the positions I am taking with regard to an interlocutor. [SLIDE: picture of me wearing a brown fleece and a long green knitted scarf loosely wrapped around my neck several times, standing in front of some vines crawling up a rock face. I am looking straight at the camera and smiling.] For example, looking attentively at my interlocutor with a smile on my face is, in my experience, an invitation to that person to contribute, to elaborate on something, to extend a thought. When I adopt this body language, I usually hope to communicate that I am an interested and welcoming interlocutor.

However, in another modality, such as electronic chat, text-message, or email, those same gestures are not easily expressed, that body language isn’t as easily perceptible, and I have to come up with different ways of communicating the positions and stances I want to convey.

And, as disability studies scholars have emphasized time and again, even in a face-to-face context, it’s important to remember that not everybody reads such in-person physical cues in the same way.

And! Even when the body is visible in an electronic interface, as it is on a video chat such as Skype or FaceTime, it still moves differently, is read differently (see, e.g., Dadas, forthcoming). When I am on Skype, for example, I often have to consciously remind myself to look at the camera, not at my computer screen, so that people get the impression of me looking at them, rather than of my eyes half-lidded looking down at my hands typing or at the screen where their faces appear at me.

AND! As I script this, I am further reminded of the many things I learn about how to communicate through interacting with people who don’t communicate in the same ways I do, or who don’t have the same preferences I do, and I am reminded how vitally important it is for those designing qualitative studies to not assume a single modality, to not assume that there is a “best” or “most important” or “most objective” way to access participants’ lived experiences, and that even for interviewers, what may feel most comfortable or “natural” is anything but.

This is a work in progress also available on my website, sites.udel.edu/kersch/presentations. You can cite it as a conference presentation.
The important take away from this set of observations about the differences in different modalities and forms of communication are these:

- When conducting DS-infused research interviews, take the time to establish the context as well as some conventions for the unfolding interview interaction, even if—perhaps especially if—your interview participants are already comfortable/familiar with that interview modality.
- Check your own assumptions about what particular communicative practices might mean and how you are signaling your positions and marking difference.
- Attend, as well, to how you are interpreting others’ utterances, gestures, and markers of difference.

Limitations of Narrative Structures
While narratives of times and moments when faculty members have disclosed their disability or had it disclosed for them by others or negotiated complex interactions in some way affected by or connected to their disability are an important means by which we as researchers can “access” disclosure, it is also important to recognize ways that such narratives are limited in what they can help us access.

--lived experience is not always easy to characterize within narrative frames

--not all disclosures are easily captured via narrative (e.g., wearing hearing aids or using a cane or a wheelchair; behaving in ways that others don’t know how to interpret or mischaracterize; having to account for or explain particular requests or needs).

--temporal orientation of narratives: we already know how the stories unfold; decision-making is explained retroactively and (in some cases) given moral significance.

--narratives are told from vantage point of disabled faculty member and they don’t necessarily account for what other people are noticing or taking up in a particular context.

Works Cited

This is a work in progress also available on my website, sites.udel.edu/kersch/presentations. You can cite it as a conference presentation.
Stephanie Kerschbaum, Assistant Professor of English, University of Delaware
“Imagining and Accessing Lived Realities in Research Interviews”
Society for Disability Studies Conference, Orlando, FL
27 June 2013


This is a work in progress also available on my website, sites.udel.edu/kersch/presentations.
You can cite it as a conference presentation.