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Recommended Citation

Ostrove, Joan and Rinaldi, Jennifer, "Self-Reflection as Scholarly Praxis: Researcher Identity in Disability Studies—Guest Editors' Introduction" (2013). *Faculty Publications*. 3.
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Guest Editors' Introduction—Self-reflection as scholarly praxis: Researcher identity in Disability Studies

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Reflections...

I [Ostrove] did my first disability studies project in 1976, although I certainly didn't think of myself as "doing disability studies" at the time. I was in Miss Ackerman's 6th grade class at North Street Elementary School in White Plains, New York. Anticipating Garland-Thomson's (2009) recent work by more than 30 years, my research paper was called "And the people stopped and stared: People's reactions to the handicapped." In contrast to my extremely poor memory for most of the other papers I've ever written (certainly pre-graduate school), I remember almost everything about this one. I remember the kind of research I did: I read lots of books, I interviewed a friend in my class whose sister had cerebral palsy, I went to the Lighthouse for the Blind and got pamphlets that described different kinds of visual impairments. I remember that I wrote out the results of my research with a fountain pen that I had to dip in real ink. And I remember that I bound it all together on pink construction paper, painstakingly tied together with a piece of yarn. I got an "A++/A++" from Miss Ackerman, who also showed it to the principal.

I don't really know why I'm so interested in disability. Well, that's not really true, but it's what I usually say if people ask (which they do). The usual answer to that question for other (temporarily) non-disabled people like myself—or at least what I perceive to be the usual answer—is personal in an explicable (and perhaps predictable?) sort of way: A

relative or a close friend has some kind of disability. But that wasn't my answer. I had no best friend in elementary school who had been mainstreamed into my class. Yes (as is true for most people), I did—and do—have disabled relatives. My great uncle had only one hand (no one ever talked about why, and I certainly never asked). My father's first cousin (that same uncle's daughter, as it happens) has Down's syndrome. But I hardly spent any time with them and didn't feel particularly close to them, although I know I felt curious about their lives. But those members of my family were not the reason I wrote that paper in 6th grade; the reasons for that paper—and my enduring interest in disability—seem much less concrete, much more... historical... and, therefore, somehow, much less legitimate.

Ever since that 6th grade project, I've been a voracious but (until relatively recently) secretive consumer of disability-related literature. I read "overcoming the odds" newspaper stories intended to elicit admiration; "tragedy befell this family" magazine articles intended to arouse pity; biographies and autobiographies of people with various kinds of disabilities intended to inspire courage, undo stereotypes, stave off pity, or simply provide another perspective on life. (Although it wasn't until college that I had a theoretical framework for my own interest in all of this, when I finally read Goffman [1959, 1963] I was elated.) I read scholarship in disability and Deaf studies, long before I "came out" as a disability studies person. All along, though, I always had the sense that there was something "wrong" with me for being so interested. It finally occurred to me that this was, in some way, a playing out of disability oppression: after all, how many times are disabled people asked, "What's wrong with you?"

I grew up in a white, upper-middle-class, Jewish family in which I felt an intense (if usually unspoken) pressure to be perfect. I was the daughter of a generation born during the Holocaust, consciously and unconsciously dedicated to "never again"—to ensuring that we should never look or act different or vulnerable in any way. Although we were proud to be Jewish and attended services almost every Friday night, upward mobility and assimilation were the name of the game. In my family (as in many others in a similar structural context) upward mobility meant perfection. Looking perfect, acting perfect, being perfect... It meant that I was very invested in looking beautiful and acting nice, and in getting good grades (ah, the irony of the "A++/A++" on my first disability studies project). It meant I hardly ever tried to do anything that I didn't think I would be good at. Despite my strong investment in all of this, I always had a critique of it, too. I knew there was something superficial and even hypocritical about it (wasn't being Jewish about who you were as a person and the good you did in the world, rather than about how you looked?). The critique didn't spare me from doggedly internalizing a need for perfection, however. And I think it was

this aspect of my upbringing that left me very interested in the lives and experiences of people who—at least in terms of the societal standards and expectations that I was raised with and encouraged to internalize—could not be "perfect."

Later I would understand this striving for perfection to be about fear and the internalization of anti-Jewish oppression, about an external pressure that had many Jews trading our distinctive culture for a "place at the table" in white Christian-dominated society. I now understand the ways that sexism and classism commodify and capitalize on the "perfect body" for sexual exploitation and for worker productivity. Provocative analyses of genetic testing and prenatal diagnosis by Meira Weiss (2002) and Yael Hashiloni-Dolev (2006) suggest that (Ashkenazi Jewish) women in Israel "hold the world record for fetal diagnostics" (Weiss, 2002, p. 2) and are "exceptionally supportive" of selective abortion and other forms of reproductive genetics such as preventing recessive gene carriers from marrying one another (Hashiloni-Dolev, 2006, p. 129). Tracing the history of the development of the Jewish state in the context of a wider historical and social representation of diaspora Jews [particularly Jewish men] as "pathological ... effeminate ... [or] impotent" (p. 15), Weiss argues that the founders of Israel aimed to construct a society populated by the "masculine, Ashkenazi, Jewish, perfect, and wholesome ... chosen body" (that women are, of course, responsible for both embodying and producing; p. 4). To achieve that goal, Weiss contends that reproductive practices among Ashkenazi Jews in Israel are intended to avoid disability and "guarantee a perfect child" (p. 2-3) [1](#).

Analyses of identity and history—my own and my people's—offer me a way to legitimize (do I really still need to do that?!) my relationship to disability studies (though they don't provide quick and easy answers to the exact question that, after many years of anticipating it, I was finally—literally—asked at a meeting at a Center for Independent Living: "What's a nice [Jewish!] girl like you doing in a place like this?"). They also led me to embark on this special issue of DSQ with Jennifer Rinaldi who, a year after I gave a talk at a Society for Disability Studies conference based on the reflection I just shared, gave a version of the talk that is now published in this volume.

I vividly remember the day I met Joan, for it was the day I gave what I thought was a disaster of a presentation. The consummate overachiever, I tend to have presentations written and rehearsed well in advance of conference days, but this day was different. I was late for my own talk, and I began out of breath. Technology fought me every step of the way. My attempt to distract with humor failed—as it turns out, I'm not very funny.

I was nervous, because the work was new to me—new after ten years spent in my scholastic comfort zones. I was nervous because the work I was presenting that day began with a sharing of self. Though I would like to think small pieces of me are sprinkled about all my writing, this day my presence in the text was deliberate and conspicuous.

And I was convinced I was doing it all wrong.

Come wrap-up, I was ready to make a bee-line to my hotel room, to tear up my notes and have a good cry. But Joan stopped me, to tell me how much she appreciated my paper, and of the panel she had organized the year before. She suggested that we might have an opportunity on our hands, for we are certainly not the only researchers in this field who wrestle with disclosure, and privilege, and vulnerability.

As an interdiscipline, disability studies offers a mode of analysis that is available to everyone and that, ultimately, illuminates important aspects of all human (and non-human) existence. Certainly, we want everyone to employ the paradigms offered by disability studies, to engage questions of normality and normalcy, the body, access and accommodation, standards of beauty, etc. But the "nothing about us without us" rallying cry from the disability rights movement (Charlton, 1998) exists as background—sometimes soft, sometimes loud—on the disability studies side. And rightly so... Histories of exploitation of research participants, of knowledge production for "management and control" rather than social transformation, plague inquiries related to disability in similar ways as they do other social identities (see Hurtado, 2010, for an analysis in the domains of race and gender). Given the history of the oppression of people with disabilities by non-disabled people, many disabled people are understandably wary of non-disabled people's participation in disability activism and, perhaps by extension, in disability studies (see, e.g., the exchange between Drake [1997] and Branfield [1998] in *Disability & Society* for a discussion of these challenges in the area of disability rights activism).

Indeed, several authors in this issue (e.g., Rinaldi, Schalk, Mogendorff, Bennett) raise tensions or opportunities related to "credibility" as a disability studies scholar that often—implicitly or explicitly—turn on some dimension of disability identity. Yet as O'Toole (this issue) points out, people's "relationship to disability" is often not a straightforward matter of "disabled" or "non-disabled."

It is with these tensions and questions in mind that we invited papers on the topic of researcher identity in disability studies. Critical identity scholars have noted the importance of a self-reflexive stance with respect to our own subject positions as a necessary ingredient toward knowledge production and effective engagement across differences of identity (e.g., Bondi, 2009; Harding, 1991; Michalko, 2002; Mohanty, 2003; Reinharz, 1992). Grounded in critiques of "objectivity," especially in the domain of science (see, e.g., Haraway, 1988), reflexivity offers a practice for paying attention to and taking account of power dynamics between the "researcher" and the "researched." The idea that knowledge is situated, rather than value-free or obtainable "from no specific position," (Morawski, 2001, p. 63) has

perhaps been one of the most influential contributions of feminist epistemology and feminist (social) science.

Self-reflexive analysis has now become commonplace in some disciplines (although it is not without its critics, including those who see it as "disastrously inward-looking and self-indulgent" [Bondi, 2009, p. 328]; see also Rinaldi, this issue). We think it is important for disability studies scholars to engage in critical self-reflection, however, given the critical role of disability identity in the field. We note with interest Rice's (2009) analysis of changes in her own body from large to "culturally acceptable" during her study of embodiment among women in which she interviewed women with a variety of body sizes, both disabled and non-disabled (see also DelBusso [2007] for a reflexive analysis of embodiment—specifically the ways her bodily practices did or did not signal "feminist" to her interviewees—in the research practice). Rice reflects,

When my body shifted over the course of conducting interviews to a culturally acceptable size, I sensed that some women were intimidated or alienated by my appearance while others were drawn into intimate exchange because of the cultural power of beauty. Many revealed this range of responses with queries such as 'Why are *you* doing this research?' and '*What*' made you interested in this topic?' While initially I believed women posed personal questions primarily because they wanted more intimate information about my body issues, I gradually began to understand that they were asking for an *ethical accounting* more than a *confessional recounting* of my reasons for conducting the research. In my conversations with women marginalized by societal misconceptions about their bodies, some subtly wondered whether I had the insight needed to revision conventional accounts and enrich understanding about living with bodily differences (pp. 253-254, italics in original).

We think that "Why are you doing this research?" and "What made you interested in this topic?" are not atypical questions asked of disability studies scholars; the answer is likely assumed to be "personal" among those with apparent disabilities and—in large part because of how marginalized disability and disabled people are in society—something that must be justified among those without apparent disabilities. This special issue is intended to offer an opportunity for a self-conscious and transparent—perhaps sometimes confessional, perhaps sometimes ethical—analysis of our own multiple identities and social positions as they relate to and inform a liberatory practice in Disability Studies.

The first article, by O'Toole, in some ways engages the questions we posed in our call for papers about reflexivity and researcher identity in disability studies most directly. By asking "what is your relationship to disability?" O'Toole implores us to engage and acknowledge—publicly—our lived experiences with respect to disability in ways that push beyond the "disabled/non-disabled" binary. She interrogates the resistance to "coming out" in relation to disability, suggesting that such practices are inevitably and ultimately a "win" for ableism. We encourage

readers to consider O'Toole's argument in relation to that of Rinaldi's, in which the request for nondisclosure is made in the context of an analysis of the limits of reflexivity and the potential consequences of coming out amidst strong—and often judgmental—pressures to disclose (especially in the context of Disability Studies graduate programs).

Papers by Bennett, Mogendorff, and Hammer directly engage the meanings of being a disabled or non-disabled disability studies researcher. Both Bennett and Mogendorff analyze the benefits and the challenges associated with what Mogendorff calls "employing experiential knowledge" in disability-related research. Bennett, writing from the perspective of a researcher with a significant speech disability, not only recounts his experiences engaging research participants, but also offers critiques of and strategies for presenting one's work (especially in conference settings) in academia, a world that not only assumes, but also puts great value on, facility with the spoken word. From her vantage point as a disabled researcher in the Netherlands, Mogendorff offers reflections on the "dilemmas of disclosure" when one has double membership in both the disability community and the research community, dilemmas that arise from wanting (and needing) both to acknowledge and transform the very real negative stigma of disability.

Hammer engages the ethnographic research process from her perspective as a sighted researcher studying gender identity among blind women in Israel. Engaging anthropology, feminist studies, and disability studies, Hammer interrogates issues of power and privilege—and her own relation to sightedness and blindness—while engaging in the "sensory endeavor" of qualitative research.

The final three papers, by Burke and Nicodemus, Moss, and Schalk, offer explorations of identification with disability/Deaf identities/studies. Burke and Nicodemus reflect on their relationship as consumer and provider, respectively, of sign language interpreting services. Their paper offers an analysis of the ways in which access to accommodation can alter identity and identification, and also reflects on the nature of "consumer-interpreter" relations that raise questions about autonomy, vulnerability, and intimacy—concepts with broad relevance to other domains of disability studies as well. Moss's narrative of "becoming undisciplined" describes and analyzes her (inter)disciplinary scholarly—and deeply personal—journey to disability studies as a person living with chronic illness. Finally, we close this special issue with Schalk's provocative analysis of "crip (dis)identification" in which she traces her own relation to disability and crip identity. Schalk is simultaneously passionate about and critical of the field of disability studies, and her intersectional disability/queer/critical race/fat studies analysis offers important opportunities for and challenges to the field.

The authors in this collection explore the importance of communication, as they share the ways in which they negotiate disability in contexts that have (usually) not anticipated it. Bennett, for instance, considers the concrete advantages and difficulties associated with speech-related disabilities, grounding his observations in his work in the field as an interviewer. When conducting interviews with blind women, Hammer found they pushed back, and their probing questions forced her

reflection. Moss, too, experiences this phenomenon of talking back; she engages in the careful work of constructing her story and notes along the way how her audiences have responded to her, and how she responds to herself, sometimes telling herself to begin anew. Burke and Nicodermus's article is itself a conversation—their interaction with one another animates the text as they consider what has been borne out of their relationship. These authors are working through the nuances to disclosure, investigating the ways in which identity is produced and perhaps transformed through discourse.

The reflexive work done here also involves honest exploration of privilege. In Hammer's research, she found herself exposed to her participants thanks to touch and interrogation. Schalk writes on her experiences as non-disabled within disability studies, and argues that our field needs to do more work to incorporate the tenets of critical race and queer studies. Some authors (Bennett, Rinaldi) note the opportunities that disability affords them, and thus trouble what it means to be privileged, while others (Burke & Nicodemus, Mogendorff, Rinaldi) express their concerns over the potential loss of status post-disclosure. It is possible to be simultaneously privileged and disadvantaged, "normal" in some ways and not in others, because identities are varied, multiple, and intersectional. These themes complicate our understanding of disclosure—the act entails not so much abruptly bursting from the closet as it does painstakingly peeling back the layers.

We think this issue offers an opportunity not only for individual authors to reflect on their own engagement with disability studies, but also for the field to engage with and about itself. We are deeply appreciative of each author's willingness to wrestle with these questions and hope you find their contributions stimulating.

Joan M. Ostrove
Jennifer Rinaldi

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Notes

1. Complementary to Weiss's analysis, Hashiloni-Dolev (2006) centers her argument about Israeli society's support for new reproductive technologies including prenatal diagnostic tests around the Israeli-Jewish bio-cultural conception of "life" and of legitimate uses of technology.

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ISSN: 2159-8371 (Online); 1041-5718 (Print)