FROM EXPERIENCE TO THEORY IN ANTHROPOLOGY'S ENGAGEMENT

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Exploring Multiple Roles and Allegiances in Ethnographic Process in Disability Culture[1]

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Abstract

The more roles the ethnographer occupies in relation to his/her informants the more likelihood that conflicts of interest and ethical dilemmas will occur. In this paper, I want to discuss several quandaries that I confronted while conducting ethnographic fieldwork with men with cerebral palsy on their search for sexual intimacy. During this research, I occupied multiple roles in relation to research participants including employee and long-time friend of my key informant, anthropologist and disability ethnographer, disability rights advocate and disability studies scholar. I will argue that critical-reflexive exploration of these quandaries borne of multiple roles and their consequent allegiances was useful not only to enrich my understanding of disabled men's sexual situation, but also led me to questioning the conceptual assumptions of both disability rights/studies and anthropology.

Recently, there is a growing awareness of the inability of the traditional fieldwork narrative to describe postmodern fieldwork situations. The Internet is providing new ethnographic terrain for some anthropologists (see, for example, Gold, 2001). Multi-site research is also becoming increasingly common (Marcus, 1998). Other anthropologists choose not to study abroad (meaning outside the U.S.) but people and issues closer to "home" (meaning inside the U.S.) despite the stigma that still exists in anthropology for studying difference at "home" (Gupta and Ferguson, 1997). An interesting development within this latter trend is the anthropologist who conducts an ethnography of an

institution or organization while also in their employment (Forsythe, 1999; Hogle and Downey, 1999). In this situation, it is not unusual for one's informants to be one's colleagues or even one's supervisors. For the anthropologist, occupying the dual roles of employee and ethnographer can involve both personal and professional dilemmas (Forsythe, 1999; and Hogle and Downey, 1999).

In fact, the more roles the ethnographer occupies in relation to his/her informants the more likelihood that conflicts of interest and other dilemmas will occur. In this paper, I want to discuss several personal and professional quandaries that I confronted while conducting ethnographic fieldwork with men with cerebral palsy on their search for sexual intimacy. During this research I occupied multiple roles in relation to research participants including employee and long-time friend of my key informant, anthropologist and disability ethnographer, disability rights advocate and disability studies scholar. I will argue that critical-reflexive exploration of these quandaries borne of multiple roles and their consequent allegiances was useful not only to enrich my understanding of disabled men's sexual situation, but also led me to questioning the conceptual assumptions of both disability rights/studies and anthropology.

The Ethnographer as Employee and Friend

It was during intimate discussions on sexuality with a disabled friend and employer, Josh (pseudonym), who has cerebral palsy, that I first conceived of doing an ethnography of disability and sexuality. In the mid to late 1990s, I lived with Josh and several other people in a large house that he owned in the East San Francisco Bay Area. We would talk into the early hours of the morning and he often brought up the barriers he felt he faced in his search for sexual intimacy. Although I conducted many in-depth interviews with 13 other men with CP as well as interviews with relevant people in their lives, Josh became my key informant. While becoming friends with one's research participants is not unusual for anthropologists in the field, recruiting one's longtime friend to be one's key informant turns the usual ethnographic sequence on its head.

My work relationship with Josh consisted in not only helping him with personal care but also in assisting him with practical actions in the world of everyday life such as taking notes in class for him and facilitating his communication in school or during various meetings. One feature of our friendship was that I often extended my assistance to him beyond what he required of his other personal assistants and into domains such as sexuality. For example, I would get him set up so that he was able to masturbate after I went upstairs to my own room. I also accompanied him to strip clubs and facilitated his communication with strippers. Prior to the formal conception of the research, I also facilitated his encounters with several sex workers. Josh's primary goal was to find someone he felt comfortable enough with to initiate a long-term sexual arrangement. If I had simply been

Josh's employee, my involvement would likely have stopped at accompanying him to strip clubs. The hook for deeper involvement was my long friendship with him.

Josh was at the time 31 years old, a man with a significant impairment who used a wheelchair to get around and an alphabet board and head pointer for communication. Still a virgin, he desperately desired some sexual experiences. Yet, he lacked the interactional skills necessary to establish an emotionally meaningful or even casual sexual relationship because of early social exclusions (see Blum et al., 1991; Mona and Gardos, 2000). He also felt that he suffered significant sexual discrimination because of his impairment. He was thus thoroughly incapable of expressing romantic or sexual interest to any of the many women that moved in and out of his life as personal assistants, friends or acquaintances. The combined influence of social and cultural impediments had rendered his sexual self-agency immobilized. As he would often tell me, "I feel blocked" (Shuttleworth, 1996, 2000a, 2001).

I presented Josh with the avenue of sexual therapy and surrogacy, but he vehemently balked at going the therapeutic route. According to him, there was nothing he needed help with, he just wanted some sexual experiences. Although the therapeutic model applied to disabled people's sexual situation can be read as a sign of their heretofore sexual exclusion, I nevertheless thought sexual therapy and perhaps some work with a sexual surrogate might actually help Josh become less blocked intersubjectively. I should add that at this point I had not started the formal phase of fieldwork and was simply conducting some off the cuff interviews with him.

Josh instead chose to purchase the services of sex workers. To him, exchanging money for sex seemed more honest than sexual therapy and sexual surrogacy. At the time, he maintained his need was simply sexual. He told me he sometimes gave up hope of ever achieving an emotionally meaningful, sexual relationship. Other times he said he would focus on that after some sexual experiences. Despite feeling ethically uneasy and experiencing a certain amount of anxiety, given Josh's situation and need for assistance in this area, I opted to help him. My assistance consisted in calling women who advertised in a local sex newspaper, explaining Josh's impairment and asking if they were open to having a session with him. If they said yes, I would facilitate the sexual encounters. Here is not the place to describe that facilitation process (see Shuttleworth, 2000a).

When the formal fieldwork started, Josh wanted me to continue helping him. Awareness of the ethical dimension and my anxiety was much heightened when the research was given certain official stamps of approval (i.e. approved by my dissertation committee, human subject's approval, etc.). Yet, Josh did not need my assistance any less in setting up these sexual encounters - he still had not found someone he felt really comfortable with.

Off-hand, I could not remember any anthropological accounts of ethnographers engaging in or helping informants engage in

illegal activities. Rabinow (1977) reports on his own encounter with a prostitute in *Reflections on Fieldwork in Morocco*. However, the way he presents it, so matter-of-factly, prostitution appears to be less negatively viewed in Morocco than in the United States. In my heightened ethical awareness, I began comparing what I was doing to an urban ethnographer assisting a drug addict in getting his/her fix. The threat of getting busted was also very real. The elaborate process of setting up first encounters revealed that these women were very much concerned about the police. Yet, despite my anxiety over the ethics of it all, I opted to continue assisting Josh. It was with a sigh of relief when about 6 months into the formal research he announced that his interest in finding a comfortable sexual arrangement with a sex worker was waning. It seemed he now wanted to concentrate on trying to establish an emotionally meaningful sexual relationship.

The Anthropologist as Community Advocate/Scholar

My increasing role in the disability community as disability advocate and disability studies scholar also created, if not an ethical dilemma, then some points of contention with my anthropological background. While I am a non-disabled ethnographer, which would usually mean being an outsider in the disability community, what obscures the clarity of this easy insider/outsider division is that I have been employed as a personal assistant for disabled men since 1984 and also boast many friends in the disability community including, as mentioned, my key informant. Does this also make me an insider? I certainly have an intimate knowledge of disabled people's practices and behaviors and I have also witnessed many instances of their stigmatization and exclusion. What is missing of course is the actual lived experience of this oppression. Nevertheless, I feel as if I straddle the insider-outsider divide with one foot placed on either side. From this anomalous position, I have become committed to disabled people's struggle for equal access in our society. Some disabled people refer to me as an ally.[2]

Now, it is common knowledge in the disability community, although not within anthropology, that many anthropologists studying disability have only weakly allied themselves with the disability rights movement and academic disability studies. For sure, identity politics within the academy endures a certain amount of stigma (Knauft, 1996). Anthropologists with their traditional emphasis on holism and longstanding relativistic tendencies may fear becoming too involved in the identity politics of this minority group would compromise their intellectual commitment to the presentation of multiple perspectives. Or they may be "uneasy about the usefulness of performative moralization in anthropology" (Cohen, 1998: xxiii). For some, too strong of an identification with others' causes on a daily basis may smell a little too much like going native. Additionally, though they may be in general agreement with the disability rights movement's goals in Western contexts, they may

fear that voicing certain criticisms based on their anthropological perspective might end up being attacked by disabled people.

And truth be said, the disability rights movement and disability studies are indeed suspicious of much previous social science research on disability. Disabled researchers such as Oliver (1990, 1996) and Abberly (1992) have argued that traditional social science research on disability, much from a medical problems perspective, has in fact played a role in the oppression of disabled people. Research that is not explicitly emancipatory has also been taken to task by disability studies scholars (Shuttleworth, 1999, 2000a; Linton, 1998; Oliver, 1990, 1996; Abberly, 1992; Stone & Priestley, 1996). Furthermore, in similar fashion to feminists and representatives of non-English speaking peoples and ethnic minorities, some disabled people, including disabled researchers, have questioned the motives and legitimacy of social science research conducted by non-group members on their lives (Shuttleworth 1999, 2000a; Oakley 1981; Bourne 1983; Oliver, 1990, 1996; Stone and Priestley 1996; Vernon 2000). Negotiating the above complexities and points of contention between my various roles, identities and disciplinary and community allegiances proves to be continually challenging (Shuttleworth, 1999, 2000a). The upside of this negotiation process is that it initiated a heightened critical-reflexivity that has multiple benefits.

Discussion

Disability ethnographers are increasingly incorporating a critical reflexivity in their writings (see, for example, Shuttleworth, 1999, 2000a; Davis, 2000; Davis, Watson, & Cunningham-Burley, 2000; Corker and Davis, forthcoming; Frank, 2000). Strongly influenced by the reflexive turn in anthropology, perhaps most notably by Clifford and Marcus's (1986) edited volume, *Writing Culture*, these ethnographers consider it of paramount importance among other reflexive issues to reflect on the sources and uses of their knowledge and methods and their multiple positions in the field in interaction with informant's subject positions. But can all this attention to fleshing out one's own motives and relations to one's research participants actually be both critically and theoretically useful in our work? I would argue that reflexively engaging with the kind of issues and dilemmas borne of multiple roles and allegiances which I outlined above positively enhanced my understanding of both informants' worlds and also helped reveal disability rights/studies and anthropological assumptions.

First, the dilemma I was faced with when asked by Josh to assist him in getting set up with a sex worker, while owed in part to anxiety about its illegality and certain feminist concerns, more strongly involved the implicit assumption that the mixing of sex and ethnography is taboo (Kulick, 1995; Ashkenazi and Markowitz, 1999). In fact, the anthropological silence concerning ethnographers' sexual experiences in the field

operates to reinforce certain moral evaluations concerning the appropriate places, times and people with which one may engage in sexual interactions. At bottom, I was anxious about whether my actions, that is, my facilitation of Josh's sexual encounters (and also to a lesser extent my accompanying him to strip clubs), were inappropriate for the context of ethnographic fieldwork. Reflecting on the reasons for this anxiety and my subsequent heightened ethical awareness, I began to really see how some contexts are deemed appropriate for sex and others are not.

What was it about sex that made it taboo in certain contexts? Why were some sexual encounters so stigmatized? A final result of this kind of critical questioning was that I was able to comprehend the degree to which sexuality is considered a personal project of the self in U.S. society and also at least one of the reasons why contexts such as surrogacy and sex work that deviate from the ideal of self-sufficiency in making sexual connections are so stigmatized. In the United States, sexuality as a reflexive project of the self relies on the rhetoric of autonomy and self-sufficiency. Those who fail to find a sexual partner in the sanctioned self-sufficient ways are thus open to negative judgement. It therefore deepened my understanding of the cultural terrain that Josh and other significantly impaired people encounter in their search for sexual intimacy, left to fend for themselves in a symbolic and structural realm of unequal opportunity in which stigmatized alternatives are sometimes seen as one's only alternatives.

I feel that the intimate data gained by assisting Josh in his search in corroboration with other men's stories has led me to an enhanced understanding of the their oftentimes struggle in searching for sexual intimacy. As a facilitator and participant-observer of Josh's quest and as an almost round the clock discussant, I was able to capture an incredible array of his thoughts and feelings on this phase of his sociosexual life leading up to his establishment of an emotionally meaningful long-term sexual relationship (he is to be married next year). If I had been simply an outsider ethnographer in the disability community for a year or two to conduct a study, this ethical reflexivity would likely never have emerged. And while recognizing the possible arguments that some might have with my decision to assist Josh, I would argue that ethnographers are confronted with these kind of ethical choices in their work more often than they usually like to admit.

A critical-reflexive understanding of my roles and allegiances as disability rights advocate/disability studies scholar and anthropologist/ethnographer is also very productive. It enables me to question both the assumptions underlying traditional anthropological notions such as culture and also the conceptual biases of disability studies' perspectives. In terms of the latter, while on the one hand incorporating a sensitivity to the disability rights movement's goal of accessibility, my allegiance to a critical anthropological perspective enables me to discern obscured aspects and underlying assumptions of the

movement and its academic offshoot that true insider researchers may miss.

While my critique is first and foremost aimed at obvious oppression in disabled people lives, I also criticize some of the concepts and practices of disability studies/disability rights: 1) for relying too much on a materialist, economic analysis of disability oppression (Shuttleworth, 1999, 2000a); 2) for down playing the hermeneutic dimension of human experience and sociocultural research (Shuttleworth, 1999, 2000a); 3) for ignoring marginal disability voices that do not fit easily within the paradigm of independent living and the social model of disability (Shuttleworth, 1999, 2000a); and 4) in terms of my own research interest for not emphasizing sexuality as a political issue (see Shuttleworth, 1996, 1999, 2000a, 2000b; also see Waxman and Finger, 1989; Shakespeare, Gillespie-Sells and Davies, 1996).

Conversely, a critical reflexivity has enabled me to more fully confront the assumptions underlying some traditional anthropological notions and principles. I have already mentioned my anxiety about mixing sex and ethnography. Anthropologists have also been authoritatively dismissive of certain developments in disability studies. For example, the claiming of disability culture is one issue that anthropologists too easily dismiss as a dilution of our traditional understanding of this concept (see Kasnitz & Shuttleworth, 1999, 2001; Shuttleworth, 2000a; Scheer, 1994). While the assumptions underlying this concept are certainly being questioned by some anthropologists (see for example, Abu-Lughod, 1990), its use by many in the discipline is still uncritical.

While initially skeptical of the claiming of disability culture by the Disability Rights Movement and academic disability studies, I have more recently come to question anthropology's rights to primary ownership of this term. Without my immersion in the disability community as a personal assistant and friend of disabled people and especially through participating in their collectivist movement and more recently disability studies scholarship, I would never have begun to reflexively question my anthropological assumptions from the perspective of the other. Indeed, in a recent article, Kasnitz (who is disabled) and I came to the conclusion that culture as a signifier must remain open to transformation in the context of people's struggles in the world (1999). If culture change is really as dynamic and fluid as recent anthropology would have us believe, then how can anthropologists privilege their concepts as static givens? I would warn anthropologists that participating in negotiations with others, even those practicing identity politics, over the meanings of some of their much beloved concepts is mandatory or else they will forfeit a say in what these term will come to mean in the larger society.

In conclusion, whereas in the age of objectivity the lack of a social role among one's informants could be construed as an asset, today a perspective from within the social field can

inform the cultural description that is the heart of ethnography. While an experiential account rendered from the ethnographer's role position in the social field can obviously benefit the ethnographic product, critical-reflexive exploration of some of the issues and dilemmas that emerge during fieldwork because of multiple roles and allegiances can also enhance ethnographic understanding and assist in interrogating the conceptual assumptions of both public and academic representatives of those one studies and also of anthropology.

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Notes

1. An earlier version of this paper was presented at the Society for Applied Anthropology's 2000 Meeting.
2. I present a phenomenological analysis of the personal assistant-disabled person relation and reflections on my role as ally as well as some of the interpretive implications of this role-relation in a previous work Shuttleworth (2000a).

References

Abberly, P. (1992). Counting us out: A discussion of the OPCS disability surveys. *Disability, Handicap & Society*, 7(2), 139-156.

Abu-Lughod, L. (1991). Writing against culture. In R. G. Fox (Editor), *Recapturing anthropology: Working in the present* (pp. 137-162). Santa Fe, NM: School of American Research Press.

Ashkenazi, M. & Markowitz, F. (1999). Sexuality and prevarication in the praxis of anthropology. In F. Markowitz and M. Ashkenazi, (Editors), *Sex, sexuality and the anthropologist* (pp. 1-21). Urbana: University of Illinois Press.

Blum, R. W., Resnick, M. D., Nelson, R. and Germaine, A. St. (1991). *Family and peer issues among adolescents with spina bifida and cerebral palsy*. Pediatrics 88(2), 280-285.

Bourne J. (1983). Towards an Anti-Racist Feminism. *Race and Class* 25(1): 1-22.

Clifford, J. & Marcus, G. (1986). *Writing culture: The poetics and politics of ethnography*. Berkeley: University of California Press.

Cohen, L. (1998). *No aging in India: Alzheimer's, the bad family, and other modern things*. Berkeley: University of

California Press.

Corker, M. & Davis, J. (in preparation). Shifting selves, shifting meanings, learning culture: Towards a reflexive dialogics in disability research. In D. Kasnitz & R. Shuttleworth, *Engaging anthropology in disability studies*.

Davis, J. (2000). Disability studies as ethnographic research and text: Research strategies and roles for promoting social change? *Disability and Society* 15(2), 191-206.

Davis J., Watson, N. & Cunningham-Burley, S. (2000). Learning the lives of disabled children: Developing a reflexive approach. In *Conducting research with children*. A. James and P. Christensen, (Editors) London: Falmer.

Forsythe, D. (1999). Ethics and politics of studying up in technoscience. *Anthropology of Work Review*, 20(1), 6-11, Special Issue: Working for them: Essays in honor of Diana Forsythe. L. Hogle and G. Downey, Guest Editors.

Frank, G. (2000). *Venus On Wheels: Two Decades of Dialogue On Disability, Biography, and Being Female in America*. Berkeley: University of California Press.

Gold, G. (2001). Searching for the cure: Virtual disability and collective action in an electronic support group. In L. Rogers & B. Swadener (Editors), *Semiotics and dis/ability: Interrogating categories of difference* (pp. 43-54). New York: SUNY Press.

Gupta, A, & Ferguson, J. (1997). Discipline and practice: "The field" as site, method, and location in anthropology. In A. Gupta, and J. Ferguson, (Editors) *Anthropological locations: Boundaries and grounds of a field science* (pp. 1-46). Berkeley: University of California Press.

Hogle, L. & Downey, G. (1999). Introduction. *Anthropology of Work Review*, 20(1), 1-5, Special Issue: Working for them: Essays in honor of Diana Forsythe, L Hogle and G Downey, Guest Editors.

Kasnitz, D., & Shuttleworth, R. (1999). Engaging anthropology in disability studies. *Position Papers in Independent Living and Disability Policy*, 1(1), May.

Kasnitz, D., & Shuttleworth, R. (2001). Anthropology and disability studies. In L. Rogers and B. Swadener (Editors), *Semiotics and dis/ability: Interrogating categories of difference* (pp. 19-41). New York: SUNY Press.

Knauft, B. (1996). *Genealogies for the present in cultural anthropology*. New York: Routledge.

Kulick, D. (1995). Introduction: The sexual life of anthropologists: Erotic subjectivity and ethnographic work. In D. Kulick and M. Wilson (Editors), *Taboo: Sex, identity and erotic subjectivity in anthropological fieldwork* (pp.1-28). New York: Routledge.

Linton, S. (1998). *Claiming disability: Knowledge and identity*. New York: New York University Press.

Marcus, G. E. (1998). *Ethnography through thick and thin*. Princeton NJ: Princeton University Press.

Mona, L. & Gardos, S. (2000). Disabled sexual partners. In L. Szuchman and F. Muscarella (Editors), *Psychological*

perspectives on human sexuality (pp. 309-353). New York: John Wiley & Sons, Inc.

Oakley A. (1981). Interviewing Women: A Contradiction in Terms. *In Doing Feminist Research*. H. Roberts, ed., London: Routledge and Kegan Paul.

Oliver, M. (1990). *The politics of disablement*. London: Macmillan.

Oliver, M. (1996). *Understanding disability: From theory to practice*. St. Martin's Press: New York.

Rabinow, P. (1977). *Reflections on fieldwork in Morocco*. Berkeley: University of California Press.

Scheer, J. (1994). Culture and disability: An anthropological point of view. In E. J. Trickett, R. J. Watts & D. Berman (Editors), *Human diversity: Perspectives on people in context*. San Francisco: Josey-Bass Publications.

Shakespeare, T., Gillespie-Sells, K., and Davies, D. (1996). *The sexual politics of disability: Untold desires*. New York: Cassell.

Shuttleworth, R. P. (1996) *An anthropological perspective on sexual and physical disability*. Paper presented at the 95th American Anthropological Association Meeting, San Francisco, November.

Shuttleworth, R. P. (1999). *Ethnographic process in anthropological research among disabled people*. Paper presented at the 98th American Anthropological Association Meeting, Chicago, November.

Shuttleworth, R. P. (2000a). *The pursuit of sexual intimacy for men with cerebral palsy*. Unpublished doctoral dissertation, University of California, San Francisco and Berkeley.

Shuttleworth, R. P. (2000b). The search for sexual intimacy for men with cerebral palsy. *Sexuality and Disability* 18(4), 263-282.

Shuttleworth, R. P. (2001). Symbolic contexts, embodied sensitivities and the lived experience of sexually relevant, interpersonal encounters for a man with severe cerebral palsy. In L. Rogers & B. Swadener (Editors.), *Semiotics and dis/ability: Interrogating categories of difference* (pp. 75-95). New York: SUNY Press.

Stone, E. & Priestley, M. (1996). Parasites, pawns and partners: disability researchers and the role of non-disabled researchers. *British Journal of Sociology*, 47, 699-716.

Vernon, A. (2000). *Disabled People Doing Disability Research*. Paper Presented at the Annual Meeting of the Society for Disability Studies, July.

Waxman, B.& Finger, A. (1989). The politics of sex and disability. *Disability Studies Quarterly* 9(3): 1-5.