

“Normals, Crazies, Insiders, and Outsiders”: The Relevance of Sue Estroff’s Medical Anthropology to Disability Studies
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Abstract: This essay explores the promising interdisciplinary connections between Disability Studies and Medical Anthropology by examining the work of long-time ethnographer and activist Sue Estroff in the context of a Disability Studies perspective and philosophy. The author provides an array of examples of how Estroff’s historical, and more recent scholarship, is relevant to Disability Studies praxis today, and suggests that Medical Anthropology as a field would benefit from utilizing a Disability Studies orientation in its own scholarship and practices.

Key Words: medical anthropology, psychiatric survivor movement, interdisciplinary

First, a note of appreciation. Sue Estroff’s work is methodologically and theoretically indispensable to my study of psychiatric discourse, women’s first person narratives of “mental illness,” and representations of female “madness” in mainstream Hollywood cinema. I am grateful to Ana Ortiz and Mark Nichter of the University of Arizona Department of Anthropology for introducing me to Estroff’s writings.

Second, the sharing of a compelling citation – employed here as part cogitative fulcrum and part assertive plea – from feminist philosopher Andrea Nicki (2001). While I differ from Nicki in my views on “the mind,” “truth,” and “mental illness,” her article’s concluding words are striking, and help to situate my discussion. She remarks:

“Feminist theory of physical disability focuses on society’s oppression of the body, of the alternate bodily states found in the physically disabled. Similarly, feminist theory of psychiatric disability concerns the oppression of the mind by a society that rejects and despises the alternate mental states found in the psychiatrically disabled. The history of Western thought has not truly been about the glorification of the mind. True appreciation will come when there is no more oppressive talk of some mental island called madness to which one in illness goes, no more morbid romanticizing of offshoots of oppression and abuse – of “mad starving artists” – or scientific mystification of fettered minds. Let there be no more beliefs that partition the complex wheel of the mind or that enforce the isolation of those suffering from oppression and mental illness” (p. 100).

Nicki’s phrasing seems to naturalize the terms and concepts “mental illness,” “the mind,” and “truth,” as if they are able to be described as stable categories with persistent and clear cultural meanings. In contrast, I believe these terms and concepts are contested, and cannot be readily interpreted through language, as their meanings depend on the context and are thus not merely transparent. I cite Nicki’s work here because I appreciate her attitude toward refuting the romanticizing of “madness” and “mad starving artists,” and her questioning of what she terms “scientific mystification of fettered minds.” Her apparent intention to undo the societal “partition[ing]” that accompanies references to “the mind” is crucial to discussions of Disability Studies in the context of Medical Anthropology and vice versa.

For thirty years, Medical Anthropologist Sue Estroff’s scholarship has accentuated the relationships between psychiatric consumer/survivor/ex-patient or “c/s/x” identity formation, social constructions of emotional difference, and public policy concerning mental health and emotional disability. Her assertion that “our psychiatric belief and treatment systems and our interactions as community members can contribute not only to the amelioration of patienthood but to its perpetuation” (1981, p. 174) directly relates to two of Disability Studies’ primary objectives: to improve the lives of disabled people; and, as advocate Simi Linton puts it, to “serve both academic

discourse and social change” (1998, p. 1).

Among our multiple projects and varied stances, promoters of Disability Studies encourage individuals and groups who self-identify as disabled to self-empower. This is partly accomplished by de-linking emotional, cognitive, and corporeal identities of “difference” from explanatory models that individualize “illness” – and by moving away from the often disturbing advancements of medicalization and “patient” dependency models – to critique and deconstruct power structures and combat stigmatization. For these reasons, I believe that Estroff’s stance regarding “patienthood” and its “amelioration” versus “perpetuation” within capitalist society may be used to build promising bridges between Medical Anthropology and Disability Studies.

In her piloting book *Claiming Disability*, Linton remarks:

“A disability studies perspective adds a critical dimension to thinking about issues such as autonomy, competence, wholeness, independence/dependence, health, physical appearance, aesthetics, community, and notions of progress and perfection – issues that pervade every aspect of the civic and pedagogic culture... Scholarship in the field addresses such fundamental ideas as who is considered a burden and who a resource, who is expendable and who is esteemed, who should engage in the activities that might lead to reproduction and who should not, and, if reproduction is not the aim, who can engage in erotic pleasures and who should not” (p. 118).

Linton rightly insisted “the voice of disabled people should be present in both disability studies and applied approaches to disabled people, but the voice should take different form in each” (p. 141). Disabled individuals must be included on curriculum committees, welcomed as leaders in the rehabilitation movement and the applied fields that affect their lives, and respectfully incorporated – rather than shunned, ignored, made exotic, or tokenized – within all societal spheres. As many Disability Studies advocates maintain, images, stories, and other representations of the disabled fashioned by disabled people must be centrally featured in all domains that pertain to disabled people’s experience. The presence of these representations ought to also help the non-disabled learn about and gain sensitivity to the disabled experience.

The mental health industry in particular needs to increasingly acknowledge, respect, and make changes based upon the powerful contributions to social justice and the critiques of the psychiatric status quo offered by members of the Disability Rights movement and the psychiatric survivor movement. Thankfully, it appears that these movements may indeed be influencing the worlds of mainstream rehabilitation and treatment. In an article published in the Spring 2001 issue of the *Psychiatric Rehabilitation Journal*, progressive social worker Priscilla Ridgway remarks, “To understand and facilitate processes of resilience and recovery, we must end the silence imposed on people with psychiatric disabilities, attend much more carefully to their personal and collective voices, and value and honor their stories” (p. 341).

The trajectory of Sue Estroff’s writing, theorizing, and advocacy was brought to public attention in the late 1970s, when she completed her dissertation on the experiences of outpatient clients in a community mental health program in Madison, Wisconsin. This work was later published as *Making it Crazy: An Ethnography of Psychiatric Clients in an American Community* (1981). One of its chapter headings is the source of the quote in my essay’s title.

In *Making it Crazy*, Estroff sought to fairly (and as accurately as possible) depict the complicated and interactive positions and perspectives of an outpatient mental health program’s staff and clients, rather than demonizing the former or patronizing the latter, as some of her professional predecessors in medical anthropology and sociology had understandably been accused of doing. The descriptive cultural study of psychiatric survivors in the wake of de-institutionalization was radical for its time.

As Disability Studies emerged, in part, from the Disability Rights movement, the c/s/x, anti-psychiatry, and Disability Rights movements simultaneously influenced Estroff's early work, and continue to influence it today. In her introduction to *Making it Crazy*, she explains some of her motivation to do the project as follows: "If Goffman and Kesey can do it in an institution, someone ought to try it outside" (p. 3). As a cultural artifact, the study may be read as a critical commentary on the era of post de-institutionalization.

Years later, Estroff returned to the Madison field site for a follow-up study, and subsequently published *Identity, Disability, and Schizophrenia: The Problem of Chronicity* (1993), a piece well-known within medical anthropology for its continued attention to her theory of role engulfment, a conceptual framework for explaining the differences between and reasoning behind what she terms "I have" versus "I am" illnesses. According to her distinctions, one does not have schizophrenia, but is (labeled) a schizophrenic. One is not an arthritic, but has arthritis – although one could say that he "feels arthritic," meaning that a bout with arthritis is in full swing.

Per Estroff, believing that one "has" or "is" something, and the linguistic conventions that label and express these states of being, are strongly influenced by the length of time one experiences symptoms, pain, difference, and so on. Thus, chronicity makes it "less and less possible to separate one's self from the stubborn presence of the impairment and resulting altered level of functioning" (1993, p. 258-9). Estroff's "sociocultural understanding of the process of chronicity" (p. 274) is aimed to "reclaim medical anthropology from biomedicine," (p. 277) but this approach "does not mean... that one rejects the call for salience in the realm of healing and suffering" (ibid.). The connections Estroff draws between disabled bodies and disabled identities may have resonance for those Disability Studies advocates who seek to simultaneously honor and complicate the identity politics around disability and difference while acknowledging that disabling moments materially happen to disabled and non-disabled people. As Laurence Kirmayer (2000) helpfully summarizes, "Medical anthropology is concerned with the interaction of social and personal constructions of illness meaning" (p.174). Estroff's attention to the daily practicalities of mental health has influenced both the tone and style of medical anthropology scholarship. In the introduction to their foundational anthology *Disability and Culture* (1995), anthropologists Benedicte Ingstad and Susan Reynolds Whyte remark, "Sue Estroff finds it characteristic of anthropology to show how people identified as deviant 'adopted, elaborated, and/or rejected their deviant identities while interacting with the culturally defined values and actions of others' [*Making it Crazy*, p. 211]. She examines the cultural values and practices of American society toward 'crazy' people and the way those so defined manipulate and use the dominant values" (p. 19).

According to Estroff, there are numerous ways that people labeled "mentally ill" strategically utilize the idea of their "deviant identities" to their advantage, and they may embrace such identities as meaningful and complex, rather than just imagining these identities as wholly problematic or as merely disruptive and difficult. Estroff asserts that "craziness" may be a choice for some and can become an ongoing performance of identity. She explains there are "rules for making it crazy," particularly if one is compelled to seek what she calls "career options" as a way of negotiating life within the realms of mainstream clinical psychiatry, and within a larger society that punishes people with stigmatic consequences for doing what they are in some ways set up to do.

In *Making it Crazy*, Estroff lists the specific "Rules for Making it Crazy" (pp. 189-190), which are assembled "to clarify the clients' perspective and working dynamics" (p. 189). Estroff notes that there are both pros and cons, and what she terms "comfort and agony," in the choice of "making it crazy" (p. 190). Before listing the 12 "rules," she remarks:

"The real cultural craziness here is that not only do we describe these persons as pathologically dependent but we contribute to their dependencies. Not only do we view them as un-integrated within the community but we isolate them by constantly

reminding them of their incompetence and by introducing them to peers [in treatment programs] with whom they may be more comfortable. We provide professionals to help these persons, as [our] society seem[s] to prefer to pay others to deal with them and thereby undermine any motivation that community members or other clients might have to participate in the caring and treatment process... We negatively value these persons, collectively and as individuals, for their differentness and their dependencies, but we leave them little chance to give us anything except 'getting better' (which means being more like us)" (pp. 188-189).

Importantly, after listing the 12 "rules," Estroff provides four "criteria for making it without craziness" (pp. 190-191), to acknowledge that some mental health clients "made it out of the system" or "reconstruct[ed] a well self" (pp. 191-191), despite what she describes as the "failures, both of persons and of the sociocultural system within which they operate" (p. 190).

I believe that the "system" to which she is referring here is the American mental health system of the mid- to late 1970s. Unfortunately, in my estimation, our current mental health system – including many (but not all) of its policies, administrators, and practitioners – is differently (if not more) problematic than it was during the 1970s.

Estroff points out that engaging with "craziness" as a disabled "identity" or "role" is often "the means by which [mental health clients] 'make it' or survive" in a fraught system and beyond (1981, p. 38). She notes that many psychiatrically diagnosed individuals pursue entitlements benefits based upon their strategic employment of a "mentally ill" identity (Estroff, et. al., 1997). Attempting to use a stigmatized identity to ones advantage and finding other ways to strategically survive in a society that stigmatizes those labeled "mentally ill" are complicated choices, and there may be serious "costs" to those who accept or who negotiate stigmatizing labels in order to claim financial benefits. However, these choices can be some among many ways of managing within an unsettling society whose hardy and ubiquitous mental health industry aims to "serve" but often simultaneously harms individuals who are labeled "mentally ill" by "experts" in that industry.

Instead of negatively judging people for making complex choices in a laborious system, Estroff is aware of – and advises that others should become more aware of – the myriad facets of adapting, working with, denying, combating, or embracing a "deviant" identity or role. She remarks that "we must remind ourselves that we are trying to understand persons who are absorbed in the creation of day-to-day living that, though negatively valued and often painful, is nonetheless rewarding" (1981, p. 198). This observation about emotionally disabled individuals mirrors one among many Disability Studies approaches toward reading triumph narratives – disabled people, psychiatric survivors among them, do not necessarily or only imagine themselves as disempowered victims of oppression who seek to heroically overcome obstacles, but are individuals with abundant identities, living with nuances and in ways that are agentic.

Estroff's commitment to respecting the rights of consumers/survivors/ex-patients and the c/s/x movement overall promotes a heightened awareness of the obligation to go beyond condescending care and well-meaning empathy to valuing the emotionally disabled within local communities and professional rehabilitative circles, and in not disrespecting individuals and groups via unethical ethnographic projects (see 1999). As someone trained in cultural anthropology, Estroff is extremely concerned with the connections between the realms of the "macro" and the "micro," and she thus engages cultural patterns while being mindful of individual uniqueness. Estroff believes in an anthropological enterprise that goes beyond studying people in context to pragmatically serve them. She is one of those rare activist scholars who actually puts into practice the idea of "giving back to the community," an approach that sometimes seems like a promise or sentimental avowal on so many scholarly lips.

Among Estroff's major concerns are the relationships between and health care seeking patterns among chronic psychiatric patients, and the ways these crucial life facets are forged in part by the mental health industry's resource allocations and professional players, and larger social policies. She asserts, "social welfare and health policies codify cultural ideas about identity, illness, and productive activity. These are then expressed in mental health care systems that – in the U.S. in particular – facilitate, indeed operate a political economy of disability construction among severely mentally ill persons" (1993, p. 251). The premise of "disability construction" is familiar to many disabled people, and has sometimes been used by Disability Studies scholars to advance a politicized social critique. While "severely mentally ill" may not be a welcome descriptor for some self-identified psychiatric survivors, Estroff's definition of disability construction could prove useful for forwarding Disability Studies and c/s/x critiques.

I interpret Estroff as envisioning a politically engaged mental health care system that is effective but that does not have its own perpetuation as a primary goal. She likewise does not want to foster a system that hinges upon the creation of patient dependencies. In her extensive work on c/s/x subjectivities and narratives, it is clear that she believes psychiatric survivors are experts within the system and ought to have the opportunity to run some things for themselves, despite the frequent and ongoing resistance to this stance on the part of many mental health administrators and professionals (see 2004). Importantly, psychiatric survivors have not waited for opportunities to be handed to them but have created opportunities for themselves through activist means. The international clubhouse movement begun by New York City's Fountain House, a rehabilitative location mostly governed by c/s/x individuals for c/s/x individuals, and other patient-led advocacy efforts have blossomed and grown and will hopefully continue to flourish in the future. Of course, there is enormous variation in what psychiatric survivors want and need, not to mention the diversity in the c/s/x world regarding political orientations, beliefs, perceptions, and feelings about being (or being labeled) "mentally ill."

In the absence of a monolithic leftist patient-led revolution that some would welcome but others would not applaud, and given ongoing capitalist realities, Estroff works to critique the mental health system from within. Her efforts invoke a savvy combination of epidemiology, patients' rights, expert attitudes, and public health policies, and she provides insights into how the mental health system – alarmingly interwoven with the prison industrial complex – could and should change, with an awareness that merely good intentions won't get us far, and there must be a profit motive behind any systemic alterations.

Disability Studies scholars and activists who are attentive to emotional and cognitive disabilities issues might benefit from surveying Estroff's reflections on the social and political-economic underpinnings of consumer/survivor/ex-patient identity formation, the pros and cons of narrative constructions of mentally ill selves, the anthropological incorporation of illness narratives and life stories, and activist anthropology's potential impact on policy making.

Although modern ethnographic work cannot be utterly disentangled from its deeply fraught socio-political history, a self-reflexive Medical Anthropology approach that is accomplished with a Disability Studies stance at its core, and a Disability Studies practice that is influenced by an anthropological orientation like Estroff's, could each offer a great deal to discussions and understandings of the connections between gender, class, sexuality, ethnicity, nation, and race in relation to disability, difference, and deviance, particularly in the scholarly and "treatment" arenas around, and the daily living of, those labeled – and/or self-identified – as "mentally ill."

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References

- Estroff, S. E. (1981). *Making it crazy: An ethnography of psychiatric clients in an American community*. Berkeley: University of California Press.
- _____. (1993). Identity, disability, and schizophrenia: The problem of chronicity. In S. Lindenbaum & M. Lock (Eds.), *Knowledge, power, and practice: The anthropology of medicine and everyday life* (pp. 247-286). Berkeley: University of California Press.
- _____. (1999). The gaze of scholars and subjects: Roles, relationships, and obligations in ethnographic research. In N. M. P. King & J. Stein (Eds.), *Beyond Regulations: Ethics in Human Subjects Research* (pp. 72-80). Chapel Hill: University of North Carolina Press.
- _____. (2004). Subject/subjectivities in dispute: The poetics, politics, and performance of first-person narratives of people with schizophrenia. In J. H. Jenkins & R. J. Barrett (Eds.), *Schizophrenia, culture, and subjectivity: The edge of experience* (pp. 282-302). Cambridge: Cambridge University Press.
- Estroff, S. E., Patrick, D. L., Zimmer, C., & Lachicotte, W. (1997). Pathways to disability income among persons with severe, persistent psychiatric disorders. *Milbank Quarterly*, 75, 495-532.
- Kirmayer, L. J. (2000). Broken narratives: Clinical encounters and the poetics of illness experience. In C. Mattingly & L. C. Garro (Eds.), *Narrative and the cultural construction of illness and healing* (pp. 153-180). Berkeley: University of California Press.
- Linton, S. (1998). *Claiming disability: Knowledge and identity*. New York and London: New York University Press.
- Nicki, A. (2001). The abused mind: Feminist theory, psychiatric disability, and trauma. *Hypatia*, 16, 80-104.
- Ridgway, P. (2001). Restorying psychiatric disability: Learning from first person recovery narratives. *Psychiatric Rehabilitation Journal*, 24, 335-343.
- Whyte, S. R., & Ingstad, B. (1995). Disability and culture: An overview. In B. Ingstad and S. R. Whyte (Eds.), *Disability and Culture* (pp. 3-32). Berkeley: University of California Press.