“Normals, Crazies, Insiders, and Outsiders”: The Relevance of SueEstroff’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 agentive.

 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.”

Diane Wiener is currently completing her doctorate in Comparative Cultural and Literary Studies at

the University of Arizona. Her dissertation engages a Disability Studies stance to critically compare

female psychiatric survivors’ written autobiographies with cinematic representations of “mentally

ill” women in the United States.

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