HEARING VOICES:
RESISTANCE AMONG PSYCHIATRIC CONSUMERS AND SURVIVORS

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The experience of mental illness in the United States is usually explained and interpreted by medical and psychiatric experts. The dominant discourse about madness in contemporary American culture is the biomedical model. It has been productive in helping remove the onus of blame from the individual, but by displacing the cause and definition to the realm of biology, it does not consider the impact of social, political, and cultural factors. The biomedical model views the experience of madness through a lens of pathology and leaves little room for alternate interpretations. Rarely are the voices of those who are labeled as such given much exposure or serious consideration.

This ethnographic study focuses on people who call themselves psychiatric survivors and/or consumers and are speaking out about their experience. These are individuals who have at one point in their life been labeled and/or hospitalized with a mental illness. My informants were primarily members of two groups in the Bay Area: Stomp Out Stigma (SOS) and the Network Against Psychiatric Assault (NAPA).

Michel Foucault's (1978:95) work emphasizes the web of power that permeates all interactions and social relations and states that where there is power there is resistance. The power to define madness has for a long time rested with the medical model and psychiatry. I was curious about the different ways people chose to re-define the experience as their own, to resist labels and attitudes toward mental illness and the openings and the limitations inherent in each of them. I chose these two groups for my fieldwork because of their contrasting philosophies and strategies of resistance.

Another area that intrigued me were definitions of "normal" and "crazy," as seen through the eyes of those who have experienced labeling. "Normality" as a concept is generally left unexamined, in many ways similar to the notion of "whiteness" as a category bereft of ethnicity or cultural background, a blank slate before which all other variations are judged as aberrations, and which takes for granted that it is the most desired category to be in.

HISTORY AND CONTEXT

Throughout the history of madness in Western society, numerous people have questioned attitudes toward, and treatment of, those labeled mentally ill. However, the first significant mobilization of voices from those actually affected by the experience has come quite recently. The late 1960's and early 1970's was a time of great social upheaval in the United States and Europe and many groups that had been disenfranchised and disempowered, including women, people of color, and gays and lesbians, formed to challenge the existing political structures and social inequalities. In 1971, the Mental Patients' Liberation Movement, as it was called by various former patients, began to emerge at a grass-roots level. The three earliest groups, in New York, Vancouver, and Boston, arose during that time. There are now many of these groups around the country which vary in their activities and political stands. These groups fall into roughly two divisions-those that identify as survivors and those that identify as consumers (Everett, 1994:63).

The San Francisco Bay Area has long been a home to dissidents of all kinds, and became fertile ground for groups resisting psychiatric labeling and oppression. The Madness Network News was published out of San Francisco starting in 1972 and served as one of the prime channels for those writing about their experiences as psychiatric survivors and led to the formation of the Network Against Psychiatric Assault (NAPA). During the 1980's, NAPA went into a long dormant period. In the past few years, there has been a movement to revive the group and its activities, which have included staging protests at the American Psychiatric Association convention and at hospitals in the Bay Area which use electroshock.

Stomp Out Stigma (SOS) was formed in 1990 when a group of people diagnosed with severe mental illness decided to form a speaker's bureau. Members of SOS are more apt to describe themselves as consumers, though not uniformly. SOS has given over 300 presentations to a variety of groups, including civic clubs, colleges, nursing schools, hospitals, high schools, and local radio and television talk shows. The main purposes of the presentations are to dispel the common myths and stereotypes about mental illness and to eliminate the stigma surrounding psychiatric disabilities through education. Carmen Lee, who helped found SOS, says she organized the group because, "We were aware that some of our services were being taken away and we realized we didn't really have anybody speaking up for us, so we decided to take it upon ourselves." SOS operates on small community grants and donations and is entirely consumer-run.

I conducted fieldwork with SOS and NAPA over an eight-month period, using participant observation and interviews to gather data. During that time, I attended SOS panels, a Candlelight Vigil to mark the start of Mental Health Awareness month, NAPA organizing meetings, protests against electroshock, and interviewed members of both groups. In this paper, I will focus on two of the themes that have arisen from the fieldwork: identity formation and resistance strategies.

IDENTITY FORMATION

How people choose to define themselves and the words they use in doing so are essential pieces of identity formation. The following brief life stories of two people I interviewed gives some idea of the ways in which they made sense of their experiences.

JAY

Jay is 39 years old. He has been a speaker on SOS panels for the past five years. He shares an apartment with a couple of other clients from the mental health agency where he receives counseling and vocational services.

Jay grew up in a small Iowa town surrounded by farm land. He remembers spending a lot of time out in the countryside. His father was an electrical lineman for the local power company. Jay attended a local community college and then went on to Iowa State University where he majored in computer science. He dropped out in his junior year "because what I now know as an illness was beginning to get to me. At the time I just thought I was extremely shy and had a lot of problems with people and making friends. I spent about the next six years in the mobile home I was living in, not working, not seeing a doctor or having medications or anything, just working out my own problems." During that time, both Jay's parents died; his mother of multiple sclerosis and his father of a heart attack. When his sister moved to California, Jay visited her and decided to move too. Jay said he was "terrified of a job interview or anything else, so I spent the next couple of years basically living in my apartment hiding from people, going out at midnight, getting groceries and stuff." He got a job in San Francisco as a computer programmer, but had difficulties with the work environment. "When a person gets isolated somewhere because everybody else wants to be at the windows or something, that was the worst thing that could happen to me because I wanted to be involved with people. . . I would walk over and talk to people, and my behavior got a little more erratic all the time because I was so desperate to connect with people. That finally got me fired."

This incident worsened Jay's sense of isolation, and he began to hear voices and feel suicidal. He said the voices "kept saying that they were going to kill me, so I went to the police. I complained because I thought it was the neighbors," he laughed. "That got me into an evaluation at psychiatric emergency and from there I became an out-patient. That's what got me onto medication, and that's what helped change everything. . . it did cut down on the anxiety quite a bit, to the point that I wasn't really that worried about going out and meeting people, which was a dramatic change for me." After this, Jay successfully held several jobs, including another computer programming job.

Jay described himself as a "client," because "I've worked so much with Caminar [a mental health agency] and most of the counselors and case managers use client because that's what their paper work is. . . It doesn't really make that much difference to me unless it's some obvious problem with people not understanding that you're actually a human being and not just a statistic. Then I don't really use any of them, I just say, 'I have this problem.'" Jay feels that the term 'psychiatric survivor' doesn't apply to him "because it seems to be something final after they decided to get out of the system or stay as far from the system as possible. I'm still pretty much involved with it, so consumer or client is what I usually use."

LEONARD
Leonard is in his 60's, and lives alone in a book-filled apartment in San Francisco. He spends much of his time compiling anthologies of quotes and writing his own pieces.

Leonard grew up in Brooklyn in a conservative Jewish family. He graduated from the University of Pennsylvania and after two years in the army, worked as a real estate agent in New York City. He moved to San Francisco in 1959, intending to continue to work in the real estate field. Leonard described himself then as "an extraordinarily conventional person-in my beliefs and in my lifestyle. Like so many people with my background in that era, I was striving to 'make it.' In terms of my goals in life, I was a fifties 'yuppie.'" He began reading books that led him toward a more spiritual view of life. One book that was particularly influential for him was Gandhi's autobiography. Leonard was inspired to practice non-violence, become a vegetarian, and grow a beard. He said, "I was thinking not only about my own well-being and that of my family, but also about how everyone could improve the quality of their lives. I soon gave up my

meager job-seeking efforts altogether and stayed alone in my apartment absorbed in solitary study and reflection. This lasted for about two years."

During this time, Leonard's parents came to visit him and were concerned about these changes. They urged him to see a psychiatrist and when he resisted, they had him committed to a hospital where he was diagnosed as a paranoid schizophrenic. During the nine months he was institutionalized, he was forced to receive a total of 85 shock treatments-50 insulin comas and 35 electroshocks. These treatments were court mandated, against Leonard's wishes. In 1974, he obtained his psychiatric records which described his symptoms as not working, withdrawal, growing a beard, refusing to eat mean, and religious preoccupation. To get out of the hospital, Leonard said, "the way I did it was to compromise, to play their game as I thought they wanted me to play it. . . I shaved voluntarily, ate some non-vegetarian foods like clam chowder and eggs, was somewhat sociable, and smiled 'appropriately' at my jailers."

After Leonard was released from the hospital, he said, "I knew almost immediately, even before I was released, that I had suffered a disaster. . . I knew that I needed to take time off to regain what I had lost as a result of all of the treatment because in addition to the memory loss and the loss of my entire college and high school education, I was unable to relearn a lot of things." He spent the next few years reading books and making hundreds of lists of words and word associations to regain his language skills. He worked in an art gallery and opened his own gallery in 1970. In 1972, he attended a lecture given by Thomas Szasz and met the editors of the Madness Network News. He contributed an article to the second issue of MNN and co-founded the Network Against Psychiatric Assault in 1974.

Leonard identifies himself as a "survivor," and also uses the term "psychiatric inmate." He draws parallels between psychiatry and brainwashing. "If you study the techniques of brainwashers and of psychiatrists who work in locked facilities or facilities where people cannot get out as easily, you will find that they are basically using the same approach. There are group therapy sessions, and they used to have thought reform groups in the brainwashing camps, you have the deprivations that go on, the restrictions on your freedom, the absence of the ability to communicate with other people outside the system so that the only people you are exposed to are in the institution, the people who agree with the dominant ideology of that institution. . . . The net effect of that kind of thing is to wear the person down, make that individual very suggestible to new information, new

ideas. . . . They make you suggestible by starving you, preventing you from sleeping, and humiliating you. Psychiatrists do the same thing. The very act of labeling someone as mentally ill means you are an inferior person."

These two people had radically different experiences with madness, and very different ways of interpreting and dealing with the experience. Jay accepts the medicalization of mental illness, and has found it to his advantage to be "in the system," receive medications, therapy, and other benefits. He is speaking out against the stigma and discrimination he experiences when looking for jobs, socializing, and from people who see him as a "statistic" rather than a "human being." Leonard never felt that he had any medical problem, or any emotional problem, for that matter. For him, he was going through a necessary part of his spiritual evolution, was not hurting anybody, but was denied his civil rights because his behaviors and attitudes were so different than what was culturally acceptable at the time. He is speaking out against the "treatment" he was forced to receive which he says caused him severe brain damage, and against the idea that a natural process should be turned into a pathology. Jay and Leonard highlight the contrast between people who call themselves consumers and those who identify as survivors. In general, consumers seek reform within existing definitions and systems of mental health while survivors take a more radical stance and question the very notion of mental illness. The delineation is not always that straightforward; as Chamberlin (1990:334) notes, former patients recognize many current opinions within their community and there are an even larger number who identify with none of the organizations and probably have never even heard of the movement.

RESISTANCE
The different philosophies and life experiences of those in NAPA and those in SOS lead toward different goals and resistance strategies. SOS, within the forum of public presentations, chooses to focus on decreasing the stigma of mental illness through telling their stories and voicing what has been helpful and not helpful to them in the mental health system, and in society. They also advocate for improved treatment services, fight against budget cuts, and seek ways to enforce the Americans with Disability Act in the work place. There are other ways that members display resistance. I often joined SOS members in their pre-presentation ritual of going out to eat at a local restaurant. I was part of some very loud and animated conversations about medications, good doctors and bad doctors, hallucinations, and other consequences of their lives. I marveled that no one in

the group really seemed to care if anyone at adjoining tables would hear these discussions about what is usually a taboo subject in a public place.

NAPA focuses its energies on political actions such as demonstrations and letter writing campaigns to legislators with the goal of ending forced treatment, drugging, and electroshock. NAPA and survivors do not place much emphasis on decreasing stigma because, as Kris explains, even the notion of the "stigma" and the efforts to combat it operates from the assumption that mental illness is a real entity which sits in a biomedical view of the world. She pointed out that attempts to "decrease stigma" reinforce the idea of "different" behavior as a disease, rather than a way of living one's life (which might be quite radical or subversive). David Oaks, who publishes *The Dendron*, a national newsletter which serves as the communication medium for survivors, noted that while other people have tried to label the movement as "anti-drug" or "anti-psychiatry," "Our common denominator is simply about being pro-empowerment and pro-choice in the rights movement."

While there are differences in world view and strategies between the consumer and the survivor movement, SOS's identity as consumers working for improvement within the system does not preclude them from critiquing aspects such as their observation that stigma and discrimination is more prevalent in the mental health system than anywhere else, and that the Alliance for the Mentally Ill (AMI), an "advocacy" group comprised mostly or parents and family members, can be very disempowering. They may have a deeply ingrained fear of biting the hand that feeds them, but they certainly nip at it with tenacity. During one pre-presentation lunch that I shared with SOS members, they talked about a recent opening on the San Mateo Mental Health Board. The position was supposed to be filled by a consumer, but one of the board members who was a family member was trying to fill it with another parent. Sharon, an SOS member, said that when this woman found out her plan was going to be thwarted, the woman "got so mad that she spit." Sharon joked that someone should have asked her if she had taken her "meds," since that's how many of the parents deal with their children when they express strong feelings. Both Carmen and Sharon said that AMI does not include very many consumer voices and does not seem to want to. Sharon suggested that AMI should be renamed "Parents in Denial." When SOS was in its early stage, Carmen said they sometimes brought a family member or professional with them to presentations, but soon stopped doing this because the group agreed that audiences might think they were coached, and they wanted to do it completely themselves.

Humor is one weapon in the arsenal of resistance for both groups. David has created a campaign called "Heal Normality." He wrote about the campaign, "After 18 years as an activist, have I snapped? As often as possible. But there's a method in this madness: Our psychiatric rights issues are so overwhelming, even terrifying, that people often tune them out, thinking they only apply to a small minority. But this campaign is about everyone. It immediately invites the magic of laughter, as it turns the tables-or in this case the clipboard. Then we can slip in messages about other campaigns, such as fighting forced electroshock." The campaign consists of posters and buttons which point out the "ten warning signs of normality." Some of these include: "Cool: you're cool, you hold everything in and always put a 'good face on it'-you never cry or laugh much, or show emotion in any way, certainly not in public. Your psychiatric label is 'tearlessnicity.' Nice: You always act nice even if you can't stand the person to whom you're talking. You never say what you're really thinking. Your diagnosis: 'inappropriate smiling.'"

David pointed out that many patterns of what we call "normal" are quite destructive. He said, "There is a lot of power to actually naming something and looking at it. I really believe that we are part of this whole social transformation. . . and that right now there is a personal and planetary crisis in terms of the extinction of species and ecocide, and it really is what is called 'normal' that is doing that. . . One of the purposes we serve is that they can say, 'Well there is this five percent that is mentally ill, and we're not mentally ill because there is the five percent.' There is a need for a scapegoat. 'There is a percent that is truly crazy, but not us, we're in control of our faculties.' As long as people polish their shoes and wake up on time and have the suit on, then all of the sudden what they're doing is not mentally ill. That's bullshit. Because if you go and make a decision that wrecks the ozone layer, that's way more disruptive and disturbed then someone who is walking in front of a car."

Many of the people I interviewed spoke about the healing they have experienced from their decision to speak out about their lives. John said, "From my own experience of being an African-American, what's really mental health is when you speak out for yourself, and you speak out when you feel like you're being mistreated or stereotyped. The same principles apply when you are a consumer. When you feel people are judging you or treating you in the wrong way, when you speak out that's real mental health." Jay said, "It's actually better therapy than I have any other way. . . because you're not talking

to a professional. You're not talking to someone who nods and says, "Okay, and what else." These people actually talk back. They ask questions and want to know, and you get to tell your story your own way, and nobody is writing down notes that say, 'behavior is such and such'. . . It's an entirely different perspective and it's opened up my life a lot."

CONCLUSION

As the researcher, my own experiences and identity were an integral part of this study. When I worked in the mental health system, I experienced much ambiguity in trying to establish egalitarian and humane relationships with my clients while at the same time having to impose some rather drastic interventions and controlling measures when it seemed as though they were in danger of hurting themselves. No doubt some of my motivation in choosing this topic is an attempt to more deeply explore some of that ambiguity and to contribute to the creation of a space and a language where some other response is possible, both from mental health professionals and the public.

John Caputo (1993), in an essay that asks how the thoughts of Michel Foucault can be applied on an institutional level, suggests the creation of a healing gesture that would view people with "mental illness" as "an Other from which we ourselves have something to learn... Such a patient would not be an object of knowledge but an author or subject of knowledge. (p. 259)" I hope that this study can help to provide mental health professionals with a new framework of thinking about the work as akin to that of an anthropologist and cultural broker—when working with people whose culture is different, there is much to be learned from both cultures, and each can help the other to learn to navigate in different realities with which they are most familiar. I know it has certainly increased my awareness of the power dynamics inherent in the existing mental health system and who is left out of the decision making process. I hope that the study will also provide information for all of us to question how we might benefit by re-casting our definition of mental health. And finally, I see this study as a celebration of the creative and diverse strategies that people use in the process of resistance to current cultural paradigms.

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