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Hearing Voices:
Resistance Among
Psychiatric Survivors and Consumers

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1. INTRODUCTION

I was evicted once, because they saw me as very high functioning, very well, pretending, and the next day I'd be in the hospital and they were frightened. So I was evicted from this in-law apartment. They had no grievance with me, the way I kept the place, or entertaining or anything. They were just frightened. In fact I was in the hospital when they evicted me. I thought that was dirty.

– Carmen, SOS

I'm starting to work on relationships, and that's a hard one, because I've never done that before. It's starting to worry me, first of all, not making a lot of money, second, not having a car or transportation, and third, the mental illness background. It's hard enough being shy and trying to get a date! Then, "Can you pick me up?" "Well, no, I don't have a car." "Where can we go?" "Well, I don't know, I don't have a lot of money." I'm starting to wonder how the hell I'm going to get my life in order from here on in.

– Jay, SOS

About three years ago, I was working as an AIDS educator outreach worker for the mental health association. . . . I went to this one particular board and care home, and the director had no idea that I was a consumer myself. . . . After I gave that presentation, [a woman who lived in the home] happened to visit one day, and we were talking, and she said that the lady who ran the board and care home was talking to her and she said, "I know John, I used to live with him." [The board and care operator] said, "You used to live with him?" She said, "Yeah, he's in the mental health system." And she told her, "I'll never have him back to the house." I was hurt, I was just pissed off that she would do that. Even though I had this valuable information that they needed to know, because I'm a consumer I can't come back to the house and give another presentation.

– John, SOS

I found the consent form at one point and it said I would get no more than 20 electroshocks, but I don't know, because they could have easily given me more. I know that I started protesting it at one point, even to the point that I would be in the room and they'd give you the prep stuff, and I'd say, "No, I don't want it." They'd say, "You need to make up your mind, because you're wasting the doctor's time." They pressured me, so I'd try to have it because I felt guilty and bad. . . . Finally I said "No more." I tried that for a long time, but they kept coercing me to get it anyway. Finally I was adamant. The anaesthetic was the thing that freaked me out the most, then I would wake up with these horrid headaches and sick and didn't know where I was, didn't know who I was.

– Ava, NAPA

Oppression has been defined as the “systematic, pervasive, routine, institutionalized mistreatment of individuals on the basis of their membership in various groups which are disadvantaged by imbalances of power in society” (Sherover-Marcuse 1986). The stories of Carmen, Jay, Ava, and John illustrate the nature of oppression of people who are defined as mentally ill in the United States. In housing, jobs, social interactions, and within the very system from which they seek help, they experience discrimination based on the assumptions in our culture about mental illness. They are often economically disadvantaged; many are unable to work either because of their disability, the lack of reasonable accommodations by employers, or the difficulty in finding a job when one is labeled as mentally ill. In social circles, people with mental illness (especially those with more obvious manifestations of it) are frequently forced to limit their friendships to those with a similar background. Their civil rights can be violated; in some situations, they are confined in hospitals and given medications, electroshock, and other treatments without their consent. In effect, the mentally ill person in the United States is marginalized from the general population and oppressed through mechanisms of isolation, avoidance, patronization, and medicalization.

Mental illness is often viewed as an individual disease rather than as a category of oppression. In the United States and many other Western countries, it is usually explained and interpreted by medical and psychiatric “experts.” Rarely do the voices of those labeled as such receive exposure or serious consideration. Because of the economic and social consequences involved, few people in American culture choose to publicly acknowledge that they have been called mentally ill. A common response to oppression is to hide the fact, if possible, that one has been given a psychiatric diagnosis, received treatment, and in some cases, been hospitalized. Another choice is to go public with the experience, resist oppression, and fight for one’s rights.

This ethnographic study explores resistance among people who identify themselves as psychiatric survivors and consumers. These are individuals who have at some time in their life been labeled with and treated for a mental illness and have chosen to speak out about their experiences.

Psychiatric survivors and consumers may be considered a part of a larger, loosely-networked group of other former psychiatric patients. This movement, which began organizing in the early 1970's, has been given various names by the people in it, including The Mental Patients' Liberation Front and The Madness Liberation Front. For the purposes of this paper, I will employ the term used by Judi Chamberlin (1990) in her account of its history: the Ex-Patients' Movement.

As an anthropologist and former mental health professional, I thought it noteworthy that many people in the mental health field, including patients, had never heard of the Ex-Patients' Movement or if they had, often did not see it as credible. Indeed, some of the people in this study can be understood as part of this Movement without even knowing about it. Furthermore, I could not locate any anthropological explorations of the voices of its participants. I saw it as an area rich in cultural critique, because members of these groups pose provocative questions about cultural definitions of mental health and illness, and work to increase awareness of discrimination and human rights violations both in the mental health system and outside of it.

In psychoanalysis, resistance is viewed as an obstruction to the therapeutic process, something to be addressed and overcome. But in this context, I was interested in looking at resistance as the healthy act of questioning and fighting against patterns of oppression experienced by a group. Michel Foucault's work emphasizes the web of power that permeates all interactions and social relations, and states that where there is power there is resistance (Foucault 1978:95). In the United States, the power to define madness has for a long time rested with psychiatry. I was curious about the various ways people have chosen to resist those definitions and re-define their life experience as their own, and the openings and the limitations inherent in each strategy. My informants were primarily members of two groups in the San Francisco Bay Area: Stomp Out Stigma (SOS) and the Network Against Psychiatric Assault (NAPA). I chose these groups specifically for their contrasting approaches to resistance. While the philosophies and resistance strategies of survivors and consumers are often quite different from each other, they share a common experience of living in the world as people who have been labeled and viewed by society as mentally ill.

I also wanted to look at definitions of "normal" and "crazy," as seen through the eyes of those who have experienced labeling. The concept of "normality" 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 different and even as aberrations, and which assumes that it is the most desired category to be in. Mental health is usually equated with an absence of symptoms. During the ten years I worked in the mental health field, I became aware of some of the assumptions that most of us carry about what we consider "normal" in our emotions, behaviors, and thoughts. I observed that in our society the definition of "normal" is narrow and the gulf between "normal" and "crazy" is wide.

As a researcher grounded in emancipatory theory and practice, I viewed this separation as a form of institutionalized oppression similar to racism, sexism, and heterosexism. As with other institutionalized oppressions, it is important to ask how this separation has wounded everyone, not just the targeted group, and what healing might be possible by some mending of this split, by building alliances across these different realities and world views. Through asking questions which draw out the experience of those who are situated in the role of mentally ill in our culture, I hoped to illuminate some of our assumptions and definitions of normality, and the limitations it may impose on *all* of us, not just those directly affected by the label.

By listening to these voices and looking at the topic through an anthropological lens, this thesis explores the questions: What forms does resistance take among psychiatric survivors and consumers? Who and what are they resisting? What does their resistance indicate about how we construct cultural ideas of mental illness and normality? What would it mean for our culture to embrace new definitions of mental health? What might some of these definitions look like? I hope the study sheds light on the oppression of people labeled as “mentally ill,” and contributes to the creation of a space and a language where other responses to madness are possible in our culture.

The thesis begins with a literature review of social, historical, and cultural perspectives on the topic. Next, I describe the methodology used in this study and how my personal and professional background inspired and affected my work as an anthropologist. This is followed by a history of the Ex-Patients’ Movement. The ethnographic material begins with profiles of the people I formally interviewed, and the groups with whom I did participant observation. Next, I examine the resistance strategies and the groups and institutions which are the targets of resistance by survivors and consumers. Finally, I look at the outcomes of this resistance: political victories, personal healing, and visions for the future. The design of this paper, then, is something of a spiral—beginning with individual stories, extending into group participation, out into the realm of cultural institutions, but always referencing back to the personal voices which animate this study. The quotes I have included are often extensive. I felt this was appropriate because this is a group of people whose words are frequently interpreted by others rather than allowed to stand on their own.

Throughout the paper, I have included stories about "Joe," a man with whom I worked when I was a mental health outreach counselor. Joe was not a member of any consumer or survivor group, but in his own way he taught me a great deal about the interface between culture and mental illness and about resistance. These stories are a reminder that while the survivors and consumers included in this fieldwork are a vocal force, there is an even larger number of current and former psychiatric patients who may have never heard of this movement and are a silent voice.

2. LITERATURE REVIEW

This literature review begins by briefly outlining the assumptions of the biomedical view of mental illness. It then surveys literature from social historians, sociologists, and anthropologists. In contrast to the disease model of biomedicine, these writings have tended to look at madness as a culturally-constructed identity which is both created and affected by society. A review of writings about oppression, resistance, and social movements follows, setting the context for examining the Ex-Patients' Movement as a challenge to the dominant discourse about mental illness.

2.1 Biomedicine

In Western culture, madness has not always been equated with illness nor with biology. Prior to the rise of medical science, Western society interpreted the experience of madness from the perspective of magic and religion. The construction of an entity called mental illness is a relatively recent phenomenon and mirrors the acceptance of a medical model based in science as the source of authority and truth in our lives. Together, biomedicine, psychiatry, and psychology are the arenas from which most cultural knowledge about madness is mediated.

Biomedicine is a model of disease based in the scientific discipline of molecular biology. It dictates that disease be dealt with as an entity independent of social and cultural context, and that behavioral aberrations be explained on the basis of disordered somatic processes. It shares fundamental assumptions with Western science, including the idea of reductionism—the view that complex phenomena can ultimately be traced back to a single primary cause; and mind-body dualism—the doctrine that separates the mental realm from the somatic realm (Engel 1977:130).

The relationship between the disciplines of biomedicine, psychiatry, and psychology in treating mental illness is complex and has changed over time. Engel (1977) and Scheff (1966) provide helpful historical and sociological background on this relationship. While psychoanalytic theories of psychiatry and psychology were accepted in the first half of this century, this has significantly shifted over the past few decades. Psychiatry has increasingly aligned itself with biomedical research and treatment, with a strong emphasis on the presumed biochemical and genetic roots of mental illness. The psychosocial approach, outlined in the writings of William Anthony (1972) and G.L. Paul (1977), has been an attempt towards more holistic treatment, but it is usually relegated to an adjunct role, with biomedical treatments remaining the primary intervention.

The biomedical model, in collaboration with the National Alliance for the Mentally Ill (NAMI), is the primary sources of public information about mental illness. NAMI is a group of over 140,000 members, made up primarily of parents and families of people diagnosed with mental illness. These two groups work closely together; much of NAMI literature is written by biomedical doctors. It is important to remember that both groups have a vested interest in conveying their meaning of mental illness: the parents in NAMI have suffered from some psychoanalytic explanations that claim that these disorders (especially schizophrenia) may be caused and affected by family dynamics; and doctors earn their livelihood based on the assumption that people with mental illness, like other diseases, need professional treatment and hospitalization. In addition, the American Psychiatric Association often receives funding from pharmaceutical companies for research and conferences—a clear conflict of interest given that psychiatrists, sometimes as highly paid consultants for drug companies, are responsible for assessing the effects of medications (Breggin 1991:344-357).

The text of the NAMI brochure on mental illness reflects the biomedical model view about schizophrenia and mental illness in general. It states: "Schizophrenia is one of the most serious and disabling of the mental illnesses. . . Their [people with schizophrenia] illness is not caused by bad parenting and it is not evidence of weakness of character. Their illness is due to biochemical disturbances of the brain." One of the best-selling books on the subject of mental illness for the general public, *The Broken Brain* (Andreasen 1984), states the tenets of this model:

- The major psychiatric illnesses are diseases
- These diseases are caused principally by biological factors, and most of these factors reside in the brain
- As a scientific discipline, psychiatry seeks to identify the biological factors that cause mental illness
- Clinical evaluation of patients involves careful history-taking, observing the course of symptoms over time, physical examination, and sometimes laboratory tests
- The biological model tends to emphasize the study and management of more serious or severe mental illnesses

- The treatment of these diseases emphasizes the use of "somatic therapies"
- Mental illnesses are not due to "bad habits" or weakness of will
- Mental illnesses are not caused by bad parenting or bad "spousing"
- The somatic therapies are very effective methods for treating many mental illnesses (Andreasen 1984:29-32).

This strong emphasis on biology has left little room for differing points of view. Dialogue with alternate opinions on causes and treatment for mental illness has been sparse. Opposing viewpoints are often ignored or even ridiculed. In his popular book *Surviving Schizophrenia*, E. Fuller Torrey (1988), a psychiatrist who strongly advocates the biological causes of mental illness, lists what he considers the 15 worst books on schizophrenia, lambasting writings that contain any consideration of social and cultural conditions, including works by Thomas Szasz, Erving Goffman, and Gregory Bateson.

2.2 The Social Sciences and Madness

The disciplines of social history, sociology, and anthropology provide a different lens for the experience of madness. Writings from these areas have provided some of the theoretical inspiration and ground for the Ex-Patients' Movement.

Several social histories outline the story of the transformation of madness as a social experience to mental illness as a medical disease (Foucault 1965; Rosen 1968; Porter 1988). One book especially relevant to this study is Michel Foucault's (1965) *Madness and Civilization: A History of Insanity in the Age of Reason*. Drawing on a wide range of sources including literature, art, philosophy, and government records, this "archaeology of madness," juxtaposes the relationship between madness and the increasing emphasis on rationality in Western thinking which Foucault calls "Reason." As people shifted their faith away from the omnipotence of God and toward human Reason, Foucault suggests that the mad took the place lepers once had as a stigmatized and excluded group in society. In the concluding chapters, he points out that the creation of the asylum was simply a more subtle but equally oppressive way for Reason to dominate madness. Throughout the book, Foucault raises the issues of the power of Reason over madness and the subject-object division practiced in medicine.

Sociologist Erving Goffman (1961) contributed important work to the field with his book *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. Based on a year of fieldwork in a large American mental institution, Goffman concluded that the most significant factor in forming a mental hospital patient was the institution, not the illness. Goffman's study impacted the formulation of public policy concerning mental health treatment. It came at a time when the political and social climate was becoming increasingly centered around the civil rights movement, and contributed to legislation of the Community Mental Health Center Construction Act signed by President Kennedy in 1963. This movement was later given the name "de-institutionalization." In his book *Stigma*, Goffman (1963) analyzed the social meaning of stigma, as experienced by people with physical and mental disorders as well as former convicts, and the stigmatized person's feelings about him or herself in relation to "normals."

Another sociologist, Thomas Scheff (1966), attempted to formulate a social system model of mental disorder which included the social context that he felt was crucial in understanding the experience. Scheff saw the psychoanalytic theory of mental illness as too narrow in its focus on the disease model: ". . . it portrays neurotic behavior as unfolding relentlessly out of a defective psychological system that is entirely contained within the body" (Scheff 1966:14). To avoid the assumption of "illness" and "disease," Scheff reframed psychiatric symptoms as instances of "residual rule-breaking," that is, violations of social norms that did not fit into any categories of defined deviance. Scheff pointed out that this residual rule-breaking could arise from diverse sources, whereas psychiatric research customarily sought a single generic source, or at best a small number of sources, for the cause of mental illness.

One of the most elaborate attempts to research mental illness cross-culturally was the International Pilot Study of Schizophrenia conducted by the World Health Organization (WHO 1979) in 1968 and follow-up studies in 1970 and 1978. The WHO project looked at two issues: the diagnosis of schizophrenia at nine different sites around the world (Denmark, India, Colombia, Nigeria, England, Russia, Czechoslovakia, Taiwan, and the United States) and the course and outcome of the illness. A potential pitfall in previous similar studies had been the varying definitions of schizophrenia, and the WHO study was the first to attempt a standardized definition. The findings of the study were unexpected: first, the general picture of symptoms of schizophrenia was fairly consistent across different cultures; from the 1,202 patients examined, 811 were diagnosed as schizophrenic using the standardized criteria, with similar groups of symptoms reported from the different field sites. But while the incidence (rate or frequency of occurrence) of schizophrenia was about the same in all sites, the prevalence (the number or proportion of cases at any one time) and prognosis of the illness were found to be significantly lower in the Third World countries. As Estroff (1993) points out, the WHO study represents one of the very few investigations of differential outcome of a disease across national and cultural boundaries. Even so, it still presumes the pathology of madness and is embedded in the biomedical model.

2.3 Anthropological Studies

Early anthropological writings focused almost exclusively on the phenomenon of madness in other cultures; only recently have American anthropologists turned an eye on their own country.

In the field of anthropology, the relationship between culture and behavior has been a theme since Benedict (1934), Mead (1939), and Sapir (1949). They and others asked questions about the links between key characteristics of a culture and the common behaviors of its members, and how these linkages might result in culturally-specific illnesses. They also examined how "psychosis" was viewed cross-culturally. In contrast to psychology, the anthropological lens leaned towards relativistic explanations that allowed for the cultural construction of normality as well as pathology.

One group of ethnographies looked at phenomena such as shamanism, trance, and possession states (Nadel 1946; Belo 1960) and recognized that personality types or behavior considered abnormal in one culture may be highly valued in another. This cultural relativist position was summed up by Ruth Benedict (1934):

> It does not matter what kind of 'abnormality' we choose for illustration, those which indicate extreme instability, or those which are more in the nature of character traits like sadism or delusions of grandeur or persecution, there are well described cultures in which these individuals function at ease and with honour, and apparently without danger of difficulty to the society. . . Even a very mild mystic is aberrant in our culture. But most people have regarded extreme psychic manifestations not only as normal and desirable,

> but even as characteristic of highly valued and gifted individuals (Benedict 1934:62).

Another ethnographic approach has been to look at the concept of madness and mental disorder from indigeneous or “emic” view points. Anthropologists have given the term "culturally patterned disorders" to the names and definitions which the people under study themselves have given to their experiences. Some of these writings include Devereux's (1961) description of Mohave terms for disorders and symptoms; the *windigo* psychosis found among the Chippewa and Cree Indians in Canada which is characterized by cannibalistic impulses and delusions (Landes 1938; Cooper, J. 1933); and the *Ghost Sickness* among the Kiowa Apache which involves delusions and fantasies (Freeman, Foulks, Freeman 1976). In Southeast Asia and Indonesia, *latah* is a disorder found primarily in women and involves a startle reaction and compulsive imitative behavior (Van Loon 1926); in the highlands of Papua New Guinea, “wild man” behavior, also known as “running amok,” affects young males between the ages of approximately 22 and 35 and is characterized by hyperactivity, running, occasional threatening and aggressive behavior, and reduction in ability to hear what is said to him or to speak (Langness 1965; Newman 1964). (The word “amok” itself comes from a condition found in Indonesia in which a brooding depression can evolve into a dangerous explosion of violence (Barnouw 1985:376).) Although these works attempted to look at these phenomena through the "native's point of view," there was still an imposition of concepts and terminology from Western psychoanalytic discourse, i.e. describing symptoms as “hysterical,” "delusional," "psychotic," and "compulsive." This cultural bias was left largely unacknowledged by the writers. Even so, the contribution of these works was an understanding that madness is culturally relative.

Some anthropologists demonstrated that psychosis could at times actually bring higher status in some Third World countries. Eliade (1972) noted that the altered states of consciousness produced by psychosis are often a prerequisite to gaining shamanic power. Silverman (1967) thought that the psychotic individual could be able to function as a shaman in these societies because “the emotional supports. . . available to the shaman greatly alleviate the strain of an otherwise excruciatingly painful (schizophrenic) existence. Such supports are all too often completely unavailable to the schizophrenic in our culture.” (Silverman 1967:29)

Social labeling and attitudes toward madness have been another area of study. In rural Sri Lanka, anthropologist Nancy Waxler interviewed psychiatric patients five years after their hospitalization. At that time, 45% of them were asymptomatic, compared to 8% in Denmark in a study conducted by the World Health Organization (Waxler 1979:176). Waxler concluded that a significant factor in their high rate of recovery was the positive social labeling model that predominated in Sri Lanka—patients were not given a perjorative label and isolated but rather continued to live in a traditional family structure and were treated by the native system. Other studies which also found treatment within a family structure to be beneficial in the outcome of schizophrenia include Guthrie and Szanton's (1976) description of folk treatment for schizophrenia in the Philippines and Kennedy's (1967) account of Nubian Zar ceremonies.

The first anthropologists to examine issues of clinical psychiatry as it was being practiced in America were Gregory Bateson (1956), William Caudill (1958), and Jules Henry (1972). Bateson's ideas about how contradictory and confused communication patterns in families contributed to schizophrenia were based in part on his earlier field studies from New Guinea and Bali. Caudill studied the sociocultural systems among psychiatric patients and staff in a mental health in-patient institution and their influence on treatment. Henry conducted participant observation with five families with children who were diagnosed as emotionally disturbed to explore interpersonal and psychodynamic factors which contributed to psychosis and adaptation.

Other studies in this area included Von Mering (1970) and Edgerton (1967).Von Mering explored the cultural premises that influenced the process of disease as expressed in institutions, including the family and extending out to clinics, hospitals, and other parts of the community. Edgerton's book, *The Cloak of Competence,* is especially noteworthy for many reasons, not the least of which is the fact that it was not considered "anthropology" by his colleagues when it first was published (Chrisman and Maretzki 1982:5). The study focused on the coping styles developed by mentally retarded persons so that they functioned at levels that exceeded the expectations of the professionals who worked with them, and thus tried to avoid the stigmatization that accompanied the label of incompetence.

The mass movement of patients out of mental hospitals and into the community during the 1960's has provided a rich area for anthropologists and other social scientists to explore. Jodelot (1991) and DeRosa (1987) examined the social representation of the mad person in society and Faberga (1972) and Ingleby (1982) studied the social construction of identity and mental illness. Sue Estroff (1985, 1989, 1991, 1993) is an anthropologist who has done extensive fieldwork in this latter area. She identifies one of the core Western assumptions about illness as the belief that it results in an alteration and/or loss of self, evidenced by sayings such as, "I don't feel like myself today," and "You haven't looked like yourself." There is then a fusion of diagnosis with identity, and mental illness becomes an "I am" disease, rather than an "I have" disease. Estroff also notes the ambivalence in the way our society deals with the mentally ill; they are on the one hand patronized for being ill, and on the other, suspected for malingering. This results in mixed messages in clinical practice, public attitudes, and governmental assistance programs. Deborah Gordon (1988) explores the question underlying this dilemma, "what is a real disease?" She demonstrates how core assumptions of the Western medical system have their roots in assumptions of Western thought. Particularly salient when looking at the treatment of, and attitudes toward, mental illness is the notion that Matter is opposed to Spirit, and reality is directly proportional to materiality. Hence, "'Real' illness corresponds to the degree to which physical traces show up in the body" (Gordon 1988:24).

Recent anthropological studies explore the paradoxical nature of mental health treatment in America today: though there is a distinct lack of evidence that medications provide long-term benefits (Warner 1994), the mental health system is profoundly influenced by biomedicine and dominated by the use of medication; treatment centers are run on the political mandate of "de-institutionalization" and yet are not given adequate funding or resources to discharge patients back to the community. Lorna Rhodes (1991, 1993) explores these ambiguities and the creative resistance that both staff and patients on an acute psychiatric unit employ when navigating networks of power. Paul Koegel's (1992) ethnographic study of homeless mentally ill was an effort to view these individuals in the broader socio-economic and situational contexts of their daily life.

2.4 Oppression, Resistance, and Social Movements

Writings related to oppression, resistance, and social movements are important in understanding the lines of thought that led to the formation of the

Ex-Patients' Movement and groups like the subject of this research, NAPA and SOS. Many of these writings have roots in analyses of colonialism. Indeed, Sally Zinman (1996), who describes herself as a psychiatric survivor, compared the plight of consumers and survivors to colonized people: “We are seen as children who can’t make decisions or animals who can’t be controlled. And we can internalize those images. The Movement is about breaking both the internal and external bonds.”

Two seminal works on colonialism are *The Wretched of the Earth* by Frantz Fanon (1963) and *The Colonizer and the Colonized* by Albert Memmi (1965). Fanon’s writing concerns the psychology of a colonized people and the role of rage and violence in effecting historical change. Memmi’s book examines the privilege of the colonizer and his troubled relationship to the people he has colonized. While the colonizer derives material benefits from his privilege, Memmi asks:

> . . . how long could he fail to see the misery of the colonized and the relation of that misery to his own comfort? He realizes that this easy profit is so great only because it is wrested from others. In short, he finds two things in one: he discovers the existence of the colonizer as he discovers his own privilege (Memmi 1965:7).

This act of colonization, of one group imposing its values and control over another for material gain and control of resources, results in oppression. Paulo Friere (1970), in his important work *Pedagogy of the Oppressed* , equates this oppression with dehumanization. However, he believes that oppression is not innate but can be overcome. He writes:

> The struggle for humanization, for the emanicipation of labor, for the overcoming of alienation, for the affirmation of men and women as persons. . . is possible only because dehumanization, although a concrete historical fact, is not a given destiny but the result of an unjust order that engenders violence in the oppressors, which in turn dehumanizes the oppressed. (p. 26)

Writings from oppression theory state that this “unjust order” negatively affects the oppressor as much, if not more than, the oppressed. Memmi writes “Colonization can only disfigure the colonizer. It places before him an alternative having equally disastrous results; daily justice accepted for his benefit on the one hand and necessary, but never consummated self-sacrifice on the other" (Memmi 1965:147).

Another important principle of these theories is that oppression is institutionalized—no one is exempt from this critique. While some in the privileged group may see themselves as "good," as not one of the oppressors, it is not a matter of individual deeds or intents. Memmi writes that ". . . the style of a colonization does not depend on one or a few generous or clear-thinking individuals. Colonial relations do not stem from individual good will or actions; they exist before his arrival or his birth, and whether he accepts or rejects them matters little" (Ibid:38).

The fate of the oppressed and the oppressor is intricately tied together. While this symbiotic relationship is damaging to both sides, it also has the potential to be liberating for both. However, liberation cannot be a "gift" from the oppressor, nor a self-achievement. It can only be gained through dialogue and a mutual process (Friere, 1970). *Both* the oppressor and the oppressed must be liberated in this process. Friere's work is based on the assumption that every human being, no matter how "ignorant" or submerged in a "culture of silence," is capable of looking critically at the world in a dialogic encounter with others. As he or she does so, the world becomes radically transformed and the person is no longer willing to be a mere object responding to uncontrollable change.

Several writers have recently applied these views on oppression to working models for unraveling its dynamics and effects (Kivel 1990; Sherover-Marcuse 1986). These models attempt to set the dialogue in a non-blaming framework. People do not "earn" mistreatment because of their differences, nor are they "born" oppressors; rather, these differences are used to justify already existing power imbalances. In this work, the group without power is called the "target group" and the group with power is the "non-target group." People can shift these power imbalances and resist oppression by being "allies" to those within their own target group. Those in the non-target group can agree to be allies to the targeted group across the power line, thereby participating in their own liberation. In this context, being an ally means refusing to accept misinformation and mistreatment, and intervening in incidents of mistreatment.

In the framework of oppression, the goal is liberation, and the path to that goal is resistance. Resistance is a term which encompasses individual and collective actions, writings, and other practices which challenge the power structures and dialogues that support oppression. Examples of resistance in other movements have included Rosa Parks' refusal to sit on the back of the bus where blacks had been confined, gays and lesbians at New York's Stonewall bar rioting in defiance of police about to arrest them because of their sexual orientation, and women gathering together in consciousness-raising groups to name patterns of oppression in a male-dominated society.

Resistance can be an occasion to creatively engage possibilities of other ways of being in the world, which are different and hopefully more liberating than those prescribed by the dominant groups. While the oppressed occupy a marginalized place in society, bell hooks (1990) finds that this separation can be potentially rich: "Understanding marginality as position and place of resistance is crucial for oppressed, exploited, colonized people. If we only view the margin as a sign marking the despair, a deep nihilism penetrates in a destructive way the very ground of our being" (hooks 1990:150).

Social movements may be thought of as collective sites of resistance to oppression. A social movement has been defined as "a formally organized group that acts consciously and with some continuity to promote or resist change through collective action" (Goldberg 1991:2). Oberschall (1973) states that, in order for social movements to form, there must be some sense of an "us" who has been wronged and a "them" who has committed the injustice. Contemporary social movements include a multitude of social protest and reform activities. The environmental, gay and lesbian, disability rights, peace, and women's movements are examples of current social movements. Cohen (1985) writes that what distinguishes them from their predecessors is an emphasis on "contesting the control of an increasing range of social activities formerly shielded from public scrutiny by tradition" (Cohen 1985:701). The explanation and treatment of mental illness is an example of this; for the most part, it has been entrusted to the medical and psychiatric profession with little critical questioning by the general public.

2.5 The Ex-Patients' Movement

There is a small body of literature that explores the Ex-Patients' Movement as a social movement. Everett (1994) proposes that the goals of psychiatric survivors and consumers are consistent with Melucci's (1985) criteria for a contemporary social movement. First, they want to create symbolic change on the way to real change, most clearly demonstrated by their insistence on representation in activities related to the mental health system. Second, they seek to expose the power relations embedded in the mental health system. One example is shifting the discussion about forced hospitalization from "a form of help" to viewing it as a human rights violation.

In one of the first books to outline the approach of the Movement, *On Our Own: Patient-Controlled Alternatives to the Mental Health System*, Judith Chamberlin (1978) writes that the Ex-Patients' Movement shares a common bond with other groups that embody emanicipatory practices, including individuals with physical disabilities, women, people of color, and gays and lesbians. She defines mentalism as "the unreasonable fear of mental patients" (Chamberlin 1978:196) and writes that, "Like racism and sexism, mentalism infects its victims with the belief in their own inferiority, which must be consciously rooted out" (Ibid:173). Mentalism is also a force that discredits non-sanctioned conduct and experience by labeling them symptoms of mental illness. An important early collection of writings from survivors and consumers is the *Madness Network News Reader* (Hirsch, Adams, et al 1974). More recent readings from the movement include *Reaching Across: Mental Health Clients Helping Each Other* (Zinman, Harp, Budd 1987), and *Madness, Heresy, and the Rumor of Angels* (Farber 1993).

The Ex-Patients' Movement draws on writings from anti-psychiatry, civil rights, Marxism, feminism, and disability rights.

The Anti-Psychiatry Movement, represented by the writings of Laing (1967) and Cooper (1970, 1971), was one of the first to develop a coherent critique of psychiatry. It declared that the social structure and the family are inherently oppressive and that madness is actually a sane response to this social oppression. By doing so, it opened up dialogue that moved the definition of madness beyond the de-politicized one presented by psychiatry. It also created space for subsequent anti-psychiatry movements to emerge. But as Frank (1979:22) notes, "Sadly, however, their writings of the 1970's have abandoned many of their own earlier insights and have, instead, degenerated into non-political directions—mystical, poetic, psychoanalytical, etc." Even some of the staunchest anti-psychiatrists say that Laing's tendency to romanticize the experience of schizophrenia was not productive, for either his patients or the movement (Breggin 1991; Brown 1974).

The American Civil Liberties movement, influenced by the writings of Thomas Szasz (1974) and Peter Breggin (1983; 1991), sees mental illness as a myth which is manufactured by our scientific and technological society. It asserts that the medical model is an inappropriate, coercive, and abusive way to deal with what are actually "problems of living," not bona-fide medical (read: biological) diseases. Thomas Szasz's work, especially his book *The Myth of Mental Illness*, has provided much ammunition for psychiatric survivors and their allies to identify practices of forced hospitalization and drugging as civil rights violations. This view has in turn been critiqued by George Engel (1977) who points out that it reproduces the mind-body, nature-nurture dualism, and leaves room for only two options: either the experience is completely biological, or completely social.

The influence of Marxist theory led another group to examine power relations and madness (Brown 1974; Kovel 1987; Newman 1991). This school of thought believes that the capitalist system forces internalization of problems and a false consciousness, which lead to alienation from self, work, and others. In this way of thinking, problems of living are not individual, but are common to all persons in a social class. Alienation is not psychological, but sociological. The role of psychology is interpreted as that of keeping the oppressed adjusted to their oppression.

Feminist inquiries of madness in society underline the power differential that exists between the psychiatrist and the female patient. In *Women and Madness* (1972), Phyllis Chesler argues that sex-role stereotypes are the root of much so-called mental illness and describes how a woman is seen as disordered if she resists being cast as self-sacrificing, compassionately maternal, unadventurous, and displays "too much" independent, creative, and assertive behavior. Other authors who explore this theme are Martin (1981), Masson (1988), and Millet (1970, 1991). Chesler points out how radical psychiatrists like Laing and Cooper continued to organize their institutes in a hierarchal and patriarchal manner, and viewed themselves as saviors to their patients rather than addressing power imbalances in the therapeutic relationship. Her critique prompts us to question whether some progressive challenges to psychiatry unwittingly reproduce the same dynamic of domination, albeit in the name of liberation.

Chamberlin (1990) states that the Ex-Patients' Movement can be considered part of the Disability Rights Movement, although in actual practice, survivors and consumers may take advantage of the disability label without claiming an identity as disabled. Davis and Linton (1995) suggest that like feminist, gay and lesbian, and ethnic studies, disability studies challenge the notion that biology destines people to their social status. When disability is redefined as a social and political category rather than a medical one, it can be understood not solely as a personal condition but rather as a source of identity and a way to organize one's experience. It can also become the starting point for social activism.

Davis and Linton (1995) point out that traditionally, disability studies has been isolated in specialized and applied fields such as psychology, rehabilitation counseling, and special education. It has been shaped by teachers, and clinicians who cast the disabled in the role of patient, client, or student. Because the academy is entrenched in a biological perspective, cultural representations and social practices are rarely considered. These perspectives are marginalized in the discussion on diversity.

Reframing the meaning of illness and disability, and questioning who gives it meaning, has been addressed in the work of Kleinman (1988). Writings about disability and disability culture have also created new possibilities and given voice to people who actually live with the experience of disability in our society (Zola 1982; Stone 1984; Campbell 1991; Shaw 1994; see also *The Disability Rag* magazine). Other accounts celebrate creative resistance movements. The Mad Hatters are a group of recovered or recovering mentally ill persons whose creative response is the use of theater and dramatic performances to deal with the subject of stigma in a highly emotionally charged way (Fink and Tasman 1992).

My search of the literature did not uncover any anthropological studies on resistance among psychiatric survivors and consumers, and few studies in any discipline which examine consumers and survivors as a social movement. Sociologist Robert Emerick (1995) points out that most research in the area has been done by psychiatrists, psychologists, and social workers whose training predisposes them to define research questions in terms of the individual and intra-individual phenomena, in the service of promoting social conformity (Emerick 1995:19). This thesis is a contribution to the literature because it defines psychiatric consumer and survivor resistance as a social movement, and as a site of cultural critique.

BEGINNINGS

Joe wore glasses as thick as cokebottles. That was one disability we shared—I too needed strong glasses or contacts and am helpless without them. Joe also had another disability. He was given the label “schizoaffective” and “chronically mentally ill” by the powers that be. Somehow we got matched up together through my job at a rehabilitation center, I in the role of “mental health outreach worker,” he in the role of “client.”

We could not have been more different, and the paths we had taken in life were completely opposite. At 40 years old, Joe was a big man at about six feet tall and weighing over 200 pounds. He usually wore blue jeans, a t-shirt, and his favorite denim vest. He liked to pick up baseball caps with the names of motorcycle or equipment companies. I was a 30 year old woman, tall and thin, trained to be a music therapist and drawn to a career in the mental health field. Yet here we were together, sitting in a coffeeshop in Eugene, Oregon, getting to know each other over a cup of coffee, a donut, and for Joe, the ever-present cigarette. As he blew smoke in my face and apologized for it, he told me that he worked for the City of Eugene and had cleaned up the dumpsters around town for the past twenty years. He told me about several of his girlfriends. He told me he had built the Inn at Otter Crest, a prestigious resort on the coast of Oregon. He told me that he was really Johnny Cash.

I listened and nodded. I’d heard it all before, not this same story and not from Joe, but variations on the theme from dozens of other folks like him, the mentally ill with whom I had worked. I was amused. I listened sympathetically. I categorized symptoms in my head. I figured out what his “psychosocial needs” would be. I started writing my treatment plan, even as we were sipping the last bit of our coffee.

3. METHODOLOGY

3.1 Personal Context

The impetus for choosing this topic comes from my own experience of working for ten years in the mental health field. After receiving a bachelor's degree in music therapy, I worked in a wide range of jobs and settings: I was a counselor in a halfway house, a music therapist in a state hospital and a nursing home, a case manager in an urban setting (New Haven, Connecticut), and a mental health outreach counselor in a more tranquil setting (Eugene, Oregon). During that time, I experienced an interesting evolution in my perspective about what I was doing.

In my naivete and enthusiasm after leaving college, I thought that I could help "cure" people of their mental illness. But after a few years doing the work, I noticed an interesting thing—my clients were actually helping me. I was continually awed by their insightful explanations of why things are the way they are, the way they saw me and honestly told me what they saw, and their innate creativity and raw spirit. I was actually envious. I was *not* envious of the way most of them had to live their daily lives in this world, especially when I worked in the state hospital. Each night I could go home and they remained there on locked wards, crammed into dormitories, in buildings permeated by the smell of urine, and attended to by “burned-out” and resentful nurses and mental health workers. No, this was not what one could call good quality of life. And yet, there was something here that was missing in so many of my interactions with “normal” people outside of the hospital walls. The same was true in the community-based settings in which I worked. I noticed that the small world that people with mental illness would create inevitably felt warmer, more spontaneous, and more honest to me than outside life. I began to wonder who would want to be "normalized" back into society if it were a place where one had to suppress one's emotions, behaviors, and thoughts to fit into the narrow spectrum of what is considered "normal"?

I began to feel more and more limited by what I was doing and the approach taken by most of the professionals with whom I worked. The point of the job seemed to be to contain people in order to avoid stepping on the toes of the "normal" folks on the outside, who would get upset and call the commitment team, and the revolving hospital door cycle would start over again. While my job required me to come up with treatment plans for "psychiatric rehabilitation" for my clients, my thoughts increasingly kept turning outward towards society: what if our culture had a "place" in it for people with mental illness? What if, instead of being ignored, avoided, locked up, feared, or pitied, there was a recognition that these just might be people who know something we don't, and an interest in learning from them?

My paradigm was further challenged by attending a large conference on disability issues in Oakland. It was a memorable event for me because it was the first time in my life I had ever experienced being a “temporarily-able-bodied” (or TAB, as people in the movement call it) minority. This was my first encounter with the Disability Rights Movement. People in wheelchairs were everywhere, whizzing past me, running over my toes, to meet their friends and network. Others were conversing with each other in sign language that I could not hear or understand. I heard one of the founders of the movement, Ed Brown, speak passionately about the rights of disabled people, and rip apart attitudes like those of Jerry Lewis, as patronizing. I remember Brown saying that it is an insult to talk about the “courage” of people with disabilities who have to go out every day and deal with “barriers” such as curbs and steps—instead of talking about courage, the movement is about demanding that these barriers go! I heard one of the founders of the Ex-Patients’ Movement, Howie the Harp, talk about reasonable accommodations on the job for people with psychiatric disabilities. This was also the first time I became aware of the Movement.

The last job that I had before returning to graduate school was unlike any I had before. I was given the mandate there to "do whatever works." I watched as my co-workers would spend months just getting to know their clients, helping them to fix broken windows in their houses and going out for coffee before ever trying to approach treatment issues. This was in radical opposition to most of my other jobs where the emphasis was on conformity on the client's part: if they didn't show up for a meeting, if they didn't want to take their medications, or if in any other way they weren't “participating” in their treatment plan, they were labeled "resistant." But at this job, the emphasis was on us earning the client's trust, not the other way around. The woman who had this position before me, Cheryl, had driven around in a car with one client for literally hours at a time when he first came out of the hospital and was talking "crazy talk" in order to develop a relationship with him that was based on trust, not coercion. She did not try to give him "reality orientation," or in any other way discount what he was saying.

I had the opportunity to develop an almost three-year working relationship with that same man. Joe was a 38 year old man who had lived on the streets for most of his life. His psychiatric diagnosis was schizo-affective disorder. In addition, Joe abused almost every substance imaginable: marijuana, alcohol, methamphetamines, sniffing gasoline and swallowing the insides of inhalers. My three years of working with Joe were filled with many moments of frustration, laughter, concern, worry, and strong heart connections with this man whose life had been so different from mine. Frequently they were all the same moment! Ultimately, we came to a place of great trust in each other, and, in a classification rare for a relationship between a "professional" and a "client", we constructed a wonderful friendship.

The healing qualities of the relationship I had with Joe were enormous, for both him and me. By the time I left that job, he had maintained a significant abstinence from substances, gotten his own apartment, and most importantly, said that he felt safe and good about his life. I attribute this healing not to any special "psychiatric rehabilitation" skills on my part, nor entirely to Joe's will to get "better" because he had expressed that many times before and kept repeating the same old patterns, but to something in the realm of the *relationship* we had constructed, the place that we helped create together for all the parts of Joe to be heard and validated.

With Joe and others I had the privilege to work with, I witnessed the very real pain that comes with "mental illness." I learned the dangers of romanticizing the experience. I sat with one man for three hours as he was curled up on his kitchen floor, his hands covering his ears, trying to hide from the demonic voices in his head telling him how bad he was. I heard him tell me that medications helped with some of the symptoms but they also made him feel less than human, and took the brilliant edge off of his creativity. At any given moment it was like walking a razor's edge for him to choose which of those realities he wanted to deal with. I also saw how living in the world under conditions of poverty and discrimination greatly exacerbated whatever "mental illness" might be present for people.

I found myself caught in the role of being the "enforcer," of keeping people safe at any cost, frequently against their will (in the form of giving them their "meds," having control over their social security money, and occasionally having them committed to the hospital). I experienced the paradox of 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. I clearly remember one day yelling in utter frustration at Joe, "You have a mental illness! You need to take your meds now!" and noticing how these words objectified him. In essence, the culturally-conditioned message he heard was that he was a defective human being. I was also painfully aware that I did not know any other response that would have been more helpful to him in that situation.

After ten years of working in the mental health profession and many similar stories, I got "burned out." But for me, the burn out did not come from directly working with people. Rather, it was a result of the tension between what were indeed situations of real crisis and mental suffering, and the cultural overlay that didn't allow the clients or myself space to maneuver into anything but a pathological definition of the experience. I returned to graduate school to study cultural anthropology, seeking a larger framework through which to view the experience of mental illness and to begin to problematize "normality."

When it came time to choose a topic for my fieldwork and thesis, I realized I had a great opportunity to revisit some of my experiences of working with people who are labeled "mentally ill." I felt that an ethnographic approach would be useful to highlight the nuances and rich complexities of an experience usually considered through the lens of psychology and medicine. I wanted to more deeply explore some of the ambiguities and to contribute to the creation of a space and a language where other responses to mental illness would be possible in our culture. I also wanted to bring out voices that are usually invalidated and silenced in our society and ask: What can we all learn from these stories?

3.2 Anthropology and the Ethnographic Approach

The anthropological lens is one that views people as embedded in the culture in which they live and largely shaped by the core assumptions which that culture holds. Culture in this case can be defined as "a set of rules or standards that, when acted upon by the members of a society, produce behavior that falls within a range of variance the members consider proper and acceptable "(Haviland 1993: 30). The way we carry these rules, standards, and assumptions is largely unconscious. In everyday language, what we are talking about as culture can manifest itself when people utter statements such as "that's just the way things are" or "that's the way we have always done things around here." The parameters of culture are not be limited to the country that we live in. It also refers to the numerous cultural identities that we are situated in every day, based on gender, ethnicity, sexual orientation, and disability. Each of these identities carries with it its own set of shared experiences and assumptions about the world.

The main anthropological research methodology is ethnography. Ethnography has been called "the art and science of describing a group or culture" (Fetterman 1989:11). An ethnography is a qualitative research method characterized by firsthand observation. The primary means of data gathering in ethnography is fieldwork, which calls for the researcher to immerse herself, as much as possible, into the world of the group being studied. Because of the extent of firsthand participation and observation, ethnography also requires critical self-reflection. In my research, I used the techniques and tools of participant observation, formal and informal interviewing, and content analysis of stories and other artifacts from the culture.

In this study, I engage in a cultural critique of the concepts of "mental illness" and "normality" in the United States. The reflections and subjective truths of those who have been labeled as such serve as a mirror for the larger culture of which they are a part, the culture of normality. Using a grounded theory approach (Glaser and Straus 1967), I valued the multiple experiences and perspectives of each of the informants in this study and tried as much as possible to identify and be aware of my own assumptions at the start of this process, and then to hold them aside and from the data gathered let findings arise directly from my informants' perspectives.

I believe that the job of the anthropologist is to raise questions through the activity of thought, and to "show that things are not as self-evident as one believed, to see that what is accepted as self-evident will no longer be accepted as such" (Caputo and Yount 1993:9), what Foucault calls the practice of problematization. By asking questions which draw out the experience of one who is situated in the role of mentally ill in our culture, we can see our assumptions about what we define as normality, and the limitations it may impose on us. Foucault also noted, "The goal of my work during the last twenty years has not been to analyze the phenomena of power, nor to elaborate the foundations of such an analysis. My objective, instead, has been to create a history of the different modes by which, in our culture, human beings are made subjects." (Dreyfus and Rabinow 1982:208). It is in this same spirit that this study inquires about the experience of people who are objectified and placed into a stigmatized category in our culture: those defined as mentally ill.

3.3 Towards an Engaged Anthropology

Recently, efforts have been made to bridge the dichotomy between "academic" and "applied" anthropology. Roy Rappaport (1995) writes,

> That such a distinction has existed is unfortunate, and we should all do whatever we can to obliterate it. For one thing, there are important, perhaps even fundamental, theoretical payoffs for anthropology in dealing with the world's disorders—not the least of which may be in conceptualizing disorder itself. (Rappaport 1995:1)

One approach to bridging this gap is "engaged anthropology." Although no formal definitions of the term have been put forth, for me, engaged anthropology has meant two things: first, bringing myself and my past experiences fully into my fieldwork and the writing process; and second, becoming involved with the people in my study in the role of an ally, a supporter in unraveling systems of oppression.

I found that my background of working in the mental health field helped with knowing the jargon and having an intimate familiarity with some of the situations that people in the study spoke about, albeit from a different perspective—that of the "professional." They were also interested in me as someone who had worked in the field and was now taking a different look at it.

There were many times throughout my fieldwork that I experienced moments of paradigm clashes between my former "mental health worker" identity and my newer "anthropologist" self. At one point, Jay, an SOS member, was talking about the benefits of speaking out at an SOS panel:

> 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.

This quote was especially salient for me, as it reminded me of times when I had been the one in the role he referred to as nodding, writing down notes, and saying, "Okay, what else?" There were other similar incidents. When I began interviewing people, I found myself "diagnosing" certain behaviors and speech patterns that I was witnessing. If someone was talking and then suddenly changed topics, in my mind I would write out, "tangential speech." If someone had a hard time sitting through the hour and a half interview, I'd think to myself, "maybe a little manic." I sat in the restaurant with SOS members and watched as they were enjoying themselves and having wine with their meals, and resisted the temptation to jump in and tell them, "You shouldn't be mixing alcohol with your medications, that will exacerbate your illness." I had not realized how pervasive was my tendency to locate problems in individuals rather than in their interactions with their environment, and to patronize them.

By learning to look and listen with an anthropological lens, behaviors and characteristics I was used to seeing as "symptoms" were now becoming fascinating manifestations of a cultural and individual self.

When I asked one of my informants, David Oaks, how I could best be an ally, he reminded me that the most important way is to get political—to think about the violations happening and to make other people aware of them through letters to the editor, protests, political activism, and voting on issues. I began to carry a stack of newsletters from the movement and whenever I got into a conversation with someone interested in the topic, I'd share a copy with them. I felt it was especially important to share this information with mental health professionals, who often do not know about the movement and who have a great deal of control and impact over the lives of survivors and consumers. I found myself deeply committed to raising people's awareness that such a movement existed, as did a dialogue that questioned commonly accepted truths about mental illness and normality.

I also found myself acting as a bridge person between SOS and NAPA, and began to feel I was doing a kind of "cross-pollination." I discovered that there was often misinformation, or more usually the case, no information, between these two groups. Many of the people who called themselves consumers had never heard of the survivor movement nor the people connected with it, and were not familiar with *The Dendron*., an international newsletter published by survivors. All of the survivors were familiar with consumers, but not specifically with SOS.

I tried to hold an ethnographic view of my informants, realizing how the context of their lives affected their choice of resistance strategies, and that there was not one "right" way of resistance. While at different times I felt more drawn to either the radical or the diplomatic forms of resistance, I tried to look for ways that both had openings and limitations and how they worked differently for different people. At the same time, I felt it was important to introduce questions to both NAPA and SOS members that could broaden their perspectives on resistance, look at their own assumptions, and give them ideas of other tools for empowerment in various situations.

Within the groups, I gave feedback on situations, sometimes using examples and strategies from the other group. Carmen asked for suggestions about how to make SOS less centered around her and more of a group run organization. I gave her ideas on writing grants that would provide a stipend or salary to future organizers, providing college credit for students enrolled through a local transitional college program, and information about joining the coalition of which NAPA was a member, in order to get more recognition and also networking. Ava shared her frustration at the lack of motivation and energy in NAPA. We talked about the dynamic of internalized oppression, and I suggested that it was very important for a resistance group to celebrate its victories, an element I noticed was missing at NAPA meetings, and told her about ways that SOS had of accomplishing that.

A question I was often asked in the course of this fieldwork was, "What does anthropology have to do with this?" I had to ask myself that question and then tried to educate others about the place that anthropology could have in examining mental health. In a society so enculturated in locating the blame, cause, and control for illness, and especially mental illness, in the individual rather than in society, anthropology has a very significant role to play. Through anthropology, I have engaged in a deeper dialogue between our cultural definitions of normality and mental illness. It has given me another lens through which to view an experience of human life rich in possibility, but severely limited by the culturally imposed categories within which we all live.

3.4 Description of Fieldwork and Techniques

When I began to formulate my thesis proposal in the spring of 1995, I only knew that I wanted to talk to people who had experienced labeling by the mental health system and were speaking out to express their feelings about it. I was not sure how to go about finding them. Once I began making contacts, I realized that it was important to set a criteria of inclusion in the study that people be members of groups that were speaking out and engaged in activism, because they had taken a distinct step in their self-identity and identification with their experience.

I first heard about SOS when they gave a presentation at the California Institute of Integral Studies. Though I was not able to attend this event, I made a note of their name and address and wrote a letter of introduction to the chair of SOS, Carmen Lee. In the letter, I explained that I was a former mental health professional now pursuing a graduate degree in anthropology, and was interested in being an ally to people speaking out about their experience. A few days later I got an enthusiastic phone call from her. She was thrilled to get the letter, and was more than happy for me to come and see what SOS did. I went to one of their presentations, explained my thesis to Carmen, and asked if she and the group would be open to me doing fieldwork with them. She agreed. Carmen also recommended I talk with two women in the East Bay who were the directors of consumer self-help groups. Both of these leads proved to be fruitless; because it was the end of the fiscal year, both women were very busy working on grants and budgets for their organizations. Carmen also suggested I write to the National Stigma Clearinghouse in New York City and ask for their collection of articles about the media and mental illness and stigma. A bulging envelope came in the mail not long afterwards.

Another one of my initial contacts, David Oaks, came from my previous work in Eugene, Oregon as a mental health counselor. Although I had heard of David and seen his newsletter, *The Dendron*, I had never met him during my three years in Eugene. I sent him a variation of the letter I had sent to Carmen, along with a short version of my thesis proposal. I followed up with a phone call and set up a time to talk with him during a trip I was going to make to Oregon. During our interview, David told me about groups around the Bay Area that were members of the Support Coalition International, a network of psychiatric survivor groups. One of these groups was NAPA. David also gave me names of people in academia who had done similar studies, and suggested some articles that would be relevant to my thesis topic. The interview with David gave me a good overview of the history and diversity of the Ex-Patients' movement.

I also began to use America On Line and discovered an entire area devoted to disability and mental health issues. One of the topics in the bulletin board area was "Labels and Stigma." Many consumers and survivors from across the nation posted comments and questions on the board. I posted an introduction there, and through this, met Kris Yates, an activist in the East Bay who said she would be happy to talk to me. Kris in turn directed me to other people who were current or former members of NAPA, including Leonard Frank.

I made a conscious choice from the beginning of my fieldwork to not include any mental health professionals in the study. When I first talked to Carmen, she suggested that I go to a mental health agency in San Mateo and talk to the director to get access to people in some of their group homes. I also decided not to do this, because I wanted to hear completely from consumers who wished to speak with me, not from people who were chosen by the mental health profession.

During the first phase of fieldwork, I tried to gain a general understanding of the purpose of SOS and NAPA. I worked on building rapport with the people in the study and participated in activities, including going to speaking engagements. I had originally intended to ask if I could "shadow" people for a week or so to get some sense of how they experienced being mentally ill in society and how they practiced resistance, not only during organized events but also in their daily lives. I decided against doing this because it seemed too intrusive. I also found that I had already gathering plenty of data through my participation in events and the individual interviews.

My data came from two methods: participant observation in the activities of each of the groups and spending informal time with group members; and structured individual interviews. I supplemented this with written material from both survivor and consumer-oriented publications.

From all the members of both groups, I chose eight people with whom to conduct in-depth interviews. I also interviewed two people who were not in SOS or NAPA—David, in Oregon, and Sue, in North Carolina—for a total of ten interviewees. I tried to select people for a diversity of age, gender, sexual orientation, ethnicity, and class. In the end, I interviewed six women and four men, two people of color, four people who identified themselves as lesbian and/or bisexual, with an age range from 24 to mid-60's, and a variety of class backgrounds.

Although my original intent was to conduct participant observation and interviews with SOS and NAPA members simultaneously, I ended up spending the first several months almost exclusively with SOS. I attended presentations with SOS from April through October 1995 and then started doing individual interviews with SOS members in September. For a variety of reasons, I was unable to conduct any fieldwork with NAPA until January of 1996, near the end of my fieldwork period. During much of the summer, there were no NAPA meetings or activities scheduled; one meeting that was scheduled was canceled; Kris Yates went to the Women's Conference in Beijing and was out of town for a month; and another NAPA member did not return my phone calls. I contacted Leonard Frank by email with a request for an interview.

The final phase of the fieldwork consisted of transcribing interviews, analyzing the data collected, re-checking some of the facts and follow up questions with interviewees, and summarizing the findings. I approached the task of analysis using a method suggested by Fetterman (1989): sifting through the transcripts and field notes, comparing and contrasting data and quotes, sorting into large categories, and uncovering common patterns and themes. I tried to make this process as collaborative as possible with those I interviewed by giving them drafts of portions of the thesis and asking for comments and critique. Their corrections were incorporated in the paper. I also invited people to write responses to the paper which I would include in the appendix, but I did not receive any of these at the time of the final draft.

3.5 The Interviewing Process

The interviewing process took two different courses depending on the group.

With SOS, I attended several panels and got to know the speakers on each one. Carmen acted as a bridge for me to get to know people. I asked five of them if they would be interested in hearing more about my thesis and doing an interview. I then sent them an information packet (see Appendix) which summarized my proposal and answered questions I anticipated they might have about the interview process. I then called them back to see if they had any further questions and to set up an interview time if they wanted to participate.

I found that the time I initially spent with SOS members, going to presentations with them, traveling in the van together, and sharing in the pre- or post-event ritual of dining together contributed much to our sense of rapport. As a result, the interviews which I subsequently conducted flowed easily. Because it was the summer and fall, I had a harvest of vegetables from my home garden which I would bring as gifts to my interviewees. Often, my informants would express concern over running out of money, especially near the end of the month, and any offerings of food were greatly appreciated. Another way I found a role in SOS was by taking care of Macky, Carmen's hearing dog, during the presentations. I'd hold his leash and make sure he had water or got out for a walk, and since Macky was the unofficial SOS mascot, my role as Macky's caretaker also helped me fit right in.

With NAPA, the process was somewhat reversed. Because there were no scheduled meetings or activities during the first part of my fieldwork, I conducted most of the interviews first. I found that I spent much time explaining my thesis and my own background during these interviews in order to give people a sense of who I was and what I was looking for. In January, the group started to meet and plan protests against electroshock at a hospital in Berkeley. I sensed some suspicion and mistrust from those who hadn't previously met me and didn't know exactly what I was doing. I tried to emphasize that I was not there just to "study" them, but to offer reciprocity and to be an ally. One woman said, "Thank God. We've been studied enough!" I made my thesis proposal available and explained my work, but what really seemed to break the ice was when I agreed to help by making some signs for the protest. When I showed up the next week at the hospital with my large cardboard "Shock Kills" sign, I was welcomed with smiles and hugs and sensed that I had passed some important test!

Interviews took place in a variety of venues, depending on where the people I interviewed felt the most comfortable. Often, this was in their own homes.

Sometimes it was in a neighborhood coffee shop or park. In David's case, the interview took place in his office, right next to the Lane County Psychiatric Hospital in Eugene. I reflected on the irony of interviewing one of the leaders of the psychiatric survivor movement so close to the hospital to which I once had brought people for commitment procedures.

Interviews were taped, with permission, and roughly followed an outline of the same questions for each interview. After the interview, I sent each person a note of thanks. My original list of questions was:

- How do you define mental illness and mental health?
- Describe what it is like for you to be called mentally ill - what kinds of reactions do you get from people, whom do you feel the most comfortable with, the most uncomfortable with?
- What are some experiences that have shaped how you think of yourself and your identity?
- What term do you use to identify yourself: psychiatric survivor, mental health consumer, client, other, or none?
- What reactions do you have when you hear yourself called other terms?
- Tell me about some incidents when you have felt excluded because of your identity as mentally ill. Describe any times when being labeled has been an advantage for you, i.e. obtaining disability benefits, in social situations, etc.
- What motivated you to get involved with this movement and begin speaking about your experience?
- What is it like to talk to the public about having a mental illness ?
- What strategies do you use when talking with people who do not know that you have been a patient or consumer - do you find yourself covering up at times?
- What strategies do you use to let someone know that you have a mental illness (or however you define it)?
- What or who do you need to be careful of when revealing this information?

As I did more interviews, I found the questions clustering in four areas and I rearranged the order of the questions to fall under these areas:

1. Background information on family, childhood, and experience with mental illness and the mental health system

2. Questions related to living with the label of mental illness
3. Questions related to the resistance and the speaking out process
4. "Visionary" questions, where I asked people to give their own definitions of mental health and illness, and a future for the world of labeled people. For this section, I encouraged people to be as grandiose as they wanted to be, which usually elicited a good laugh.

The structure of the interview evolved as the interviews progressed. While working with the same general questions, I found that they needed to be modified somewhat for certain people, because of the assumptions laden in my questions. Some NAPA members literally could not answer a question like, "Describe what it is like for you to be called mentally ill," because they did not identify with that term. Instead, I became interested in knowing if there was ever a time that they did accept their role as "mentally ill," and their diagnosis, and if so, what factors led them to a different interpretation of their situation.

When I wrote my proposal, I was particularly interested in resistance to exclusion by the general public rather than just the mental health system, and attempted to design my questions to address that area. I quickly found that I was forcing the material away from what was particularly meaningful for the respondents. They kept returning to talk about "the system," because that is what their lived experience was primarily about. A few people commented on ways that the system is a microcosm of the larger society and its values, but their everyday reality is or has been in the system. Because people spent so much time with others in the system, either as friends or professionals, or in the case of survivors, felt that they were damaged by it, that is what *they* focused on, and so I tried to follow their lead.

I anticipated that my previous background as a mental health professional would be a factor in the interviews and fieldwork. I found it generally to be an asset rather than a liability, but was well aware, especially with NAPA, that not all my informants had a positive view of mental health professionals. I was also concerned that people might feel that I was assessing them psychologically, so I addressed that issue in the interview information packet. I found the most helpful technique was to be completely honest about my own story, and present questions and dilemmas from my personal experience. I also made it clear that I was seeking ways in which I could be an ally to the movement, that I was not interested in studying it simply for the sake of my own academic goals.

One of my interview questions pointed to a limitation of this study. When I asked what reactions people had when they were called "mentally ill," nearly everyone said it doesn't happen to them very much anymore except in the context of working with mental health professionals. They have either learned how to pass well enough, or are not obviously symptomatic, so that the situation does not arise. Jay noted that he would have had a different answer if I interviewed him while he was in an acute mental crisis. So one of the fundamental issues I was looking at, the experience of being mentally ill in America, was constrained by the group of people I chose to answer that question. The responses I got were reflections on past memories rather than immediate experiences.

3.6 Reliability and Validity

Reliability is the extent to which a study can be replicated by other researchers and yield similar findings (Kirk and Miller 1986:19). In this study, I have tried to address this issue by giving a detailed account of methods used, and also by conducting the fieldwork over a significant period of time, in this case, eight months. I also gave copies of portions of the thesis to interviewees to review for accuracy and comments about my findings. Their feedback came back primarily in the form of factual corrections, which I incorporated into this study.

Validity is the extent to which a study comes up with accurate findings (Kirk and Miller 1986:19). This issue was addressed by using multiple sources for gathering data: people I interviewed, members of SOS and NAPA whom I did not interview but who are included in the data as part of my participant observation, and written materials from the survivor and the consumer movement (including *The Dendron* newsletter, the National Empowerment Center Newsletter, the National Association for Rights, Protection, and Advocacy Newsletter, reports from the National Stigma Clearinghouse, and the mental patients' bill of rights.) I also used triangulation, testing one source of information against another to see if there could be alternate explanations or interpretations. For example, when I heard one person tell me that he experienced a shift in his identity toward the role of “mentally ill person,” I incorporated that question in the interview to see if that held true for others.

3.7 Ethical Concerns

During my fieldwork, participants were made aware of my role as an ethnographer when I introduced myself to them. I explained the nature of the research and told them that their involvement in the project was voluntary and confidential. I obtained written permission from the participants with whom I conducted individual taped interviews [Appendix A]. If the participants had legal guardians, the permission of the guardian was obtained. I assured participants that they had the option of not answering questions that they did not want to answer. I also assured participants that they could withdraw from the project at any time, and that the data they had contributed would be deleted upon their request.

I offered those whom I interviewed the option to use their real names in the study. I felt that a potential benefit of the study for the participants was the empowerment that comes from having a forum in which to voice one’s story, especially important in this case as psychiatric consumers/survivors are rarely allowed to speak for themselves. Using one’s own name was a recognition that some of them might view this thesis as another forum for speaking out about their experience.

For those who were members of SOS or NAPA but were not interviewed, pseudonyms were used, in accordance with AAA guidelines on anonymity and confidentiality. There were certain cases where people had chosen to have their real names used, but certain information could have been potentially damaging to them or their financial welfare. In these cases, I either changed the name or obscured identifying characteristics.

I informed participants that if they had any questions or concerns about the research they could contact me, or, if they were experiencing difficulty with me, they could contact the Chair of the Human Research Review Committee at the California Institute of Integral Studies.

A potential risk of the study was the possibility of stirring up strong emotions related to reflections on being in a stigmatized group; however, this risk was mitigated by the fact that everyone in this study had already chosen to be part of activist groups and decided to talk about their life experiences to others in that context. I let them know that I was available to process the experience after the interview, if needed. I talked to several of them afterwards and no one reported any negative consequences. In fact, several commented that the experience had been healing and even “therapeutic” for them.

In the interest of reciprocity, I offered my services as a volunteer and office consultant to the group with whom I worked the closest, SOS. Every two weeks or so, I spent time with Carmen and assisted with computer skills and grant writing. I also provided transcripts of interviews to any of my informants who requested them.

4. HISTORY/CONTEXT

Throughout the history of madness in Western society, numerous people have questioned the attitudes toward, and treatment of, those defined as “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 Ex-Patients’ Movement (also called the Psychiatric Survivors’ Movement and the Mental Patient’s Liberation Front) began to emerge at a grass-roots level. The three earliest groups, the New York Mental Patients’ Liberation Project (MPLP), the Vancouver Mental Patients’ Association (MPA), and the Boston Mental Patients’ Liberation Front (MPLF) arose almost simultaneously but independently from each other.

Everett (1994) posits that the Ex-Patients’ Movement is the fourth in a series of attempts at mental health reform, the first three being the asylum movement, the mental hygiene movement, and deinstitutionalization. The 19th century asylum movement, led by Quaker Samuel Tuke, was an attempt to create alternatives to prevailing treatments of the time which consisted largely of extremely painful restraints. Tuke established an asylum where he developed a new approach to “curing” madness known as “moral treatment.” This treatment was the recreation of a family-like environment in which patients could retreat from society and return to health. While this approach was in one sense more humane than previous treatments, Foucault wrote of the need to re-evaluate the meanings assigned to Tuke’s work:

> . . . [the] liberation of the insane, abolition of constraint, constitution of a human milieu–these are only justifications. The real operations were different. In fact, Tuke created an asylum where he substituted for the free terror of madness the stifling anguish of responsibility. . . The asylum no longer punished the madman’s guilt, it is true; but it did more, it organized that guilt, it organized

> it for the madman as a consciousness of himself, and as a non-reciprocal relation to the keeper (1965:247).

During this period in the United States, Dorothea Dix led a similar effort and established hundreds of asylums across the country. Though the asylums were originally envisioned as small homes in the country, their scale became larger in order to accommodate more people, and by the end of the 19th century they were overcrowded, deteriorating, and staffed by workers who were frequently unskilled and abusive (Rothman, 1970).

In the early 20th century, the mental hygiene movement was formed, inspired by the writings of ex-patient Clifford Beers. In his book *A Mind that Found Itself,* Beers detailed abuses he had experienced in the hospital. This led to the formation of the National Committee on Mental Hygiene. This committee promoted the belief that "insanity was an illness which could be prevented by clean living, defined as the promotion of a well-trained mind, devoid of impure thoughts" (Everett 1994:58), and sought to improve treatment conditions in hospitals. However, Beers' critique lacked any questioning of the value of psychiatric treatment or incarceration, and instead had the effect of legitimizing psychiatric intervention and institutionalization. As Everett notes, while the language used to discuss insanity, now called mental illness, had become more respectful, attitudes toward the mad remained essentially the same. In addition, the focus on early detection and treatment led to a new group of people becoming institutionalized: the middle class. This caused further crowding of hospitals and a decline in care.

This overcrowding, the introduction of psychotropic drugs, and the growing civil rights movement contributed to the third wave of reform: deinstitutionalization. In 1963, President John Kennedy signed into United States law the Community Mental Health Center Construction Act which required funding for community mental health centers and services. The idea was noble but not well-executed and woefully inadequate for those who needed it most. Many patients were discharged from hospitals into communities with very little support services. Many became homeless, lived in conditions of poverty that exacerbated their symptoms, and ended up in the hospital again. In addition, medications did not produce the promised "cure" and many continued to experience psychosis and found themselves frightened and alone (Minkhoff 1987). At the same time, it was a kind of liberation and a beginning step toward the idea that people should be treated in the "least restrictive" setting, a concept not used before in the medical model.

The Ex-Patients' Movement, as it arose in the late 1960's and early 1970's, was characterized by two guiding principles: exclusion of non-patients and consciousness raising (Chamberlin 1990:325-326). Groups that made initial attempts to include non-patients "almost always quickly dropped their liberation aspects and became reformist" (Ibid:325). Like the women's movement and the gay liberation movement, the Ex-Patients' Movement soon began to organize around the principle of self-definition and self-determination. Consciousness raising provided people with a forum to talk about their experiences of abuses and discrimination in the mental health system and society, and to see these events as patterns of oppression rather than as solely individual problems and difficulties.

Chamberlin (1990) notes that it is important to recognize that the Ex-Patients' Movement is not the same thing as anti-psychiatry. She writes, "'Anti-psychiatry' is largely an intellectual exercise of academics and dissident mental health professionals There has been little attempt within anti-psychiatry to reach out to struggling ex-patients or to include their perspective" (Chamberlin 1990:324). The defining feature of the Ex-Patients' Movement is that its leadership and membership is composed entirely of just that: ex-patients.

In a speech about the history of the movement given a consumer conference in 1996, Sally Zinman said that these early groups fought for self-determination for patients in mental hospitals who were forcibly given drugs, electroshock, lobotomies, and insulin comas. At the time, there was no representation of patients in any decision-making body or process that concerned their welfare. These groups communicated through a newsletter called the *Madness Network News*, and held annual conferences on psychiatric oppression. Because few interested people had sufficient travel money, many hitchiked to these conferences and camped outside. The Movement in its nascent days was loosely-organized, de-centralized, and almost anarchic. The groups in it refused to receive funding from outside sources because, as Zinman (1996:personal communication) states, "we were so clear about self-determination and choice that we would not accept an agenda from anybody else—even ourselves!"

These early groups engaged in radical political activity; at the 1980 American Psychiatric Association convention, survivors tied themselves together in front of the building to protest their exclusion from meetings where decisions were being made about them without their input; at one hospital, they threw pig brains at psychiatrists to protest lobotomies. These groups were also separatist and refused to allow participation by psychiatrists and other mental health professionals. A famous incident relates a conference where a group of "radical" psychiatrists (who subscribed to the ideas of R.D. Laing) were thrown out. Zinman said, "It was not foolish of us to do what we did; we started out as a colonized people, totally unequal in partnership. We had to be by ourselves, support each other, empower each other" (Ibid: personal communication).

There are now many of these groups around the country which vary in their activities and political stands. Everett (1994:63) identifies two divisions of the movement—those that identify as "survivors" and those that identify as "consumers." 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 may never have even heard of the movement. While there is great diversity in the movement, Zinman (1996) summarizes the common bond as "believ[ing] that people have the right to define the experience the way they perceive it."

The names that these groups choose to call themselves reflect the diversity of their views. Chamberlin (1990:328) writes, "'Ex-patient' was a controversial term because it appeared to embrace the medical model; *Madness Network News* promoted the use of 'ex-psychiatric inmate' . . . clearly the individuals labeling themselves 'inmates" or 'survivors' took the more militant stance."

Self-help groups are another constituency in the movement. There are more than 3,000 of these groups across the country. They are based on a non-hierarchal, non-medical model and composed completely of survivors and consumers. Their services usually include a combination of drop-in centers, work programs, and supported living situations.

In recent years, there have been changes in the movement, many of them the consequence of changes in the mental health system prompted by the activism of ex-patients. Government money is now mandated to be set aside for patient and self-help groups, and some have begun accepting funding in order to strengthen their programs. There has also been growth into a more centralized organizational form. Because there is more representation of consumers on mental health boards, professionals and consumers engage in a more collaborative decision-making processes. This has led to some people and groups dropping out of the movement, or being on the fringes, because they see these changes as co-optation by the system they were trying to resist.

The mental health field has mixed reactions to psychiatric survivors and consumers. On the one hand, more working partnerships have been established between professionals and survivors/consumers, and they are acknowledged as a powerful force in their own advocacy and recovery. But some psychiatrists and other mental health professionals also attempt to distinguish consumer groups from survivor groups and discount the latter. Torrey writes,

> Responsible consumer groups should not be confused with the much smaller group of 'psychiatric survivors,' as they call themselves, who are militantly opposed to psychiatry in general and to involuntary hospitalization and medication in particular. This antipsychiatry group denies the overwhelming evidence that schizophrenia is a brain disease and in general has adopted the positions of Drs. Szasz and Laing (1988:292-293).

This distinction is rather simplistic since many consumers would also oppose involuntary hospitalization and medication, and some survivors do choose to take medications.

The two groups with whom I conducted fieldwork, Stomp Out Stigma (SOS) and the Network Against Psychiatric Assault (NAPA), are both located in the San Francisco Bay Area. This region 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*, published out of San Francisco starting in 1972, served as one of the prime channels for those writing about their experiences as "psychiatric survivors" and led to the formation of NAPA. Leonard Frank, an informant in this study, was one of the founding members. During the 1970's NAPA mobililized around the issue of electroshock; many of its members report having been given forced electroshock. In 1975, the group was instrumental in the passage of legislation that regulated the use of electroshock in the state of California (Frank 1990: 495). During the 1980's, NAPA went into a dormant period but has recently become active again.

SOS was formed in 1990 when a group of people diagnosed with severe mental illness decided to form a speaker's bureau. 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 member-run. Members of SOS are more apt to describe themselves as consumers, though not uniformly.

5. JOURNEYS THROUGH MADNESS:
PERSONAL STORIES OF RESISTANCE

How people choose to define themselves and the words they use in doing so are essential pieces of identity formation. The first section of my interview questions focused on biographical information and terminology people used to identify themselves. The following ten brief life stories are presented as a way of introducing the people with whom I conducted formal interviews, and also to give some idea of the number of ways in which they made sense of their experience.

5.1 NAPA MEMBERS/SURVIVOR-ORIENTED

Leonard

Leonard Frank is in his 60's, and lives in a book-filled apartment in San Francisco. He helped to found NAPA in 1974 and remains involved in the group. He spends much of his time now compiling anthologies of quotes and writing his own pieces, many of which have been published in journals and magazines.

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. When he moved to California in 1959, he said, "I was only intent on making a living, establishing myself with a real estate license, getting caught up in the social world. That's what I was into, pretty much like anyone else with my background would have been." He began reading books that led him toward a more spiritual view of the world. 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 remembers that practicing non-violence

> . . . began to affect my thinking on virtually everything. I began to re-evaluate everything from A to Z, from childhood to family relations, everything, politics, economics, I saw the exploitation of society. I no longer bought into Americans as the good guys and everyone else as the enemies. Whenever we struck out and hit somebody they had it coming to them, that kind of approach. That was very revolutionary. . . .

He went through a two year period of solitary study and reflection as he was exploring this new world unfolding to him. His money eventually ran out. He said about this time, “It certainly was ‘withdrawal,’ but to my mind, it was the most positive kind of experience that could have happened. It was what I needed to do at that particular moment in my life. I had to pull back and re-think the person I was in order to become the person I could be.”

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 with paranoid schizophrenia. In 1974, he obtained his psychiatric records which described his symptoms as not working, withdrawal, growing a beard, refusing to eat meat, and religious preoccupation. Leonard was hospitalized in October 1962, at the same time as the Cuban Missile Crisis. He recalls,

> Castro was a real problem for the United States and I read later that Lyndon Johnson’s idea of dealing with Castro at that time was to capture him, lock him up, cut off his beard, and give him a good spanking. And here I was. I had a beard. I don’t think I looked like him exactly, but we both had dark hair and I was tall, and having this beard. I don’t know this for a fact, there was never an allusion to it, but I can just imagine what may have been going on in their minds. “Here’s another wise guy who wants to be a Castro, we’ll fix his ass.” Right at that very time, and even if they didn’t think of me that way, they thought of me as a difficult person who was obnoxious, and then they labeled me as “crazy” to justify locking me up.

During the nine months he was institutionalized, he was forced to receive a total of 85 shock treatments–50 insulin comas and 35 electroshocks. 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 including 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 with a friend 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, co-founded the Network Against Psychiatric Assault in 1974.

Leonard identifies himself as a “survivor,” and also uses the term “psychiatric inmate.” He said,

> I personally feel just like the survivors of the concentration camps. I don’t want to draw too close a parallel between the Nazi Holocaust and the psychiatric institution, but there are parallels that can be drawn. It’s not totally far-fetched. There are more than fifteen million people who have undergone electroshock since it’s inception fifty years ago. There were only six million Jews killed in the holocaust. Those fifteen million electroshock survivors all came out of their experience with a piece of their brain missing, and that’s also a kind of murder, a spiritual genocide.

Kris

Kris Yates, who identifies herself as a “survivor” and a “lesbian feminist,” is a member of NAPA and has been instrumental in reviving the group over the past few years. She recently had her writing published in an anthology of stories by women psychiatric survivors, *Beyond Bedlam* (Grobe, 1995).

Kris grew up in Tennessee. Her mother was a single parent who worked to support two children. Kris remembers feeling depressed in her adolescence, and her mother took her to a minister for counseling, but she never had any involvement with the mental health system. In her mid twenties, Kris worked as a waitress and then used money she had saved to travel through Europe and India for three years. During the last year and a half of that journey, she became increasingly stressed from traveling alone, and got severely physically sick in Morocco. While in India, she was taken to the Hospital for Mental Diseases in New Delhi. She cannot remember exactly what led up to this, a gap in time she attributes to the electroshock she was forced to receive there. While in the hospital and trying to make some sense of her experience, Kris remembered an encounter she had a few years before while working as a waitress. She had gone to a gallery and met Leonard Frank, who gave her a copy of the *Madness Network News*. At the time, she recalls, “I had no interest. I was not an activist. I wasn’t even a feminist. This weird guy, Leonard Frank, at a gallery, had given me this newspaper and talked at me a lot about Thomas Szasz. I really could have cared less.” But she says that memory

> . . . was crucial. Here I was in this hospital. People were holding me down, putting needles in me. I hated being drugged. I was really terrified as soon as the drugs wore off. I was wild, and they'd do it again. It was really like being in prison. It was horrible. . . [Then] I remembered reading the *Madness Network News*. . . . I remembered that and it was so powerful to think that someone knew that this was wrong. That influenced me a lot. . . It was like a beacon in the distance to hold on to, to get out of there. Because otherwise I would have thought it was all me.

When Kris was discharged a couple of weeks later, she was escorted back to the United States by a man from the American embassy. Upon her return she was put in a locked ward in a hospital on Staten Island. After getting out of that hospital, Kris never again used services in the mental health system. She received individual therapy, and later got involved in co-counseling. Kris recently received her Master's in psychology from Holy Names College in Oakland and is now facilitating women's groups as well as taking part in NAPA events and organizing.

Kris said the label of mental illness is "not useful. It feels hurtful, because it's not a term that I even use. I've pretty much rejected all those labels. I'll call myself a psychiatric survivor, but I generally don't use those labels, even in referring to other people." She has a strong reaction against the word "consumer," and sees it as a "weird made-up term from the system to make it look like we are empowered."

Ava

Ava Chanté de l'Esprit, 31 years old, learned about NAPA during the past year. She lives in a house in Berkeley. She has a degree in music and has partially completed a master's degree in counseling. Ava's first and last names, which she chose for herself last year, mean "Alive or living one, bird-like, sung from the spirit." In addition to her political activism, Ava sings in three choruses, does solo singing, and is pursuing a career in opera. She is also completing an anthology of writings about resistance for survivors of abuse and patriarchy.

Ava grew up in Livermore, California, where her father was a nuclear physicist and her mother a housewife. Ava said, "I ended up in the mental health system growing up in a completely dysfunctional family. A lot of family denial. I am an incest survivor, which started out basically when I was an infant." Ava described herself as being the "identified patient" in her family, a role she took on by "standard acting out, standard crying for help." She used alcohol and drugs and self-mutilated. Her parents saw these behaviors as problems rather than signs of the deeper issue—incest. At the age of fourteen, Ava said, "I saw a therapist because my parents came home one day and threatened to lock me up in a mental hospital unless I started seeing a psychiatrist they had found. . . . I said, 'Fuck you, I'm not going to go to the psychiatrist.' I ran away for a night, talked to a friend, and got my own counselor."

Several events were the catalyst for Ava's first hospitalization at the age of 27: the death of her brother (who was one of her abusers), working with an unskilled therapist whom Ava felt did more damage than good, ending a four year relationship and coming out as a lesbian, and confrontations with her family about the incest and abuse which were met with denial. Through a series of hospitalizations from 1992 to 1993, Ava became increasingly frustrated by her "treatment." She said,

> When the incest was written down, it was always pathologized as I read my case notes. . . . they wrote, "the alleged abuse," or "she thinks she was abused," or "she consistently believes that this thing happened to her." Complete disregard for what did happen. . . . even to the point in sessions where they would make me not talk about it, not talk about my family because it was "upsetting" me too much. . .

Ava recalled, "I had no validation of what I'd been through. Nothing at all. Of course I wasn't getting any better, because nobody in my reality, nobody in society, nobody in the whole political system, nobody in the world was saying, 'Yes, oh my God that's awful, we believe you, it happens all the time.'" While at Alta Bates/Herrick Hospital in Berkeley, Ava's doctor told her that the only way she could be helped was to receive electroshock. "They said I was an 'extreme case and a difficult patient' and what was wrong with me was biological, it wasn't emotional, it wasn't environmental, it wasn't societal, it was me." She felt pressured into signing the consent form, and received at least 20 ECT's. Although most of her memory of the time is lost, she does clearly remember one ECT session when, before being given the anaesthetic, her doctor said to her, "This can be a very good treatment for people like you who are too intelligent and creative, to help you function better in the world."

Ava described her experience of the memory loss that came in the aftermath of her ECT sessions:

> It's losing myself. Losing my identity. That's what people don't get. . . . I didn't just lose the ability to know where my car keys are. . . . People say, "Why do you remember that so clearly, but you don't remember that?" Like I'm lying. I explain it like a fire that comes through and wipes out, like the recent fire in Marin. Some houses were completely wiped out and other houses were standing, and others were charred halfway to the ground. To me, that's how my memories are. They don't have control when they put electricity to your brain. . . . it's this fire that randomly goes in and just burns up some things. That's like my memories. Some are intact, some are completely gone. It wiped out who my friends were. . . . All I have is a sense, some where in me, and that's the hardest part, that I knew who this person was, and I have a sense whether I liked them or not. I don't know where I knew them from, I don't know why I knew them, I don't know what we did together. . . . But harder than that is losing who I am. . . . As I first woke up from it, in the middle of it, I would look in the mirror and I knew I didn't know who I was any more. But I still didn't have a sense that I was any body. I just knew that I didn't know who I was and I felt like I wasn't anybody.

Ava was unaware that there was a movement of ex-patients until her girlfriend told her about Kris Yates. Through Kris, she learned about NAPA and quickly started organizing meetings and protest actions. Ava now identifies herself as a "psychiatric survivor." She said,

> Even though there are parts of me that still feel like it must be me, the main part of me, I completely understand that it's a societally imposed issue, and it's not about me at all, and it's about our society who is really hot on denial, and really hot on pathologizing individuals and not looking at the system as a whole.

David

David Oaks has been involved in the psychiatric survivor movement since the 1970's. He now lives in Eugene, Oregon where he is one of the organizers of the Support Coalition International. Along with publishing *The Dendron* newsletter, the main medium of communication for the movement, David is also involved in the environmental and peace movements.

David grew up in a working class, Eastern European neighborhood on the south side of Chicago. He is a second-generation Lithuanian. David attended a Jesuit high school and then went to Harvard on a Teamster scholarship, where he subsequently experienced his first psychiatric hospitalization. About Harvard, he said, "I was excited about going there, but when I went there, a lot caught up with me because I spent a lot of my time just being able to survive the environment. . . When I went to Harvard, there I was pretty isolated, low social skills, competitive, ornery, with all these low-key upper class people in jeans acting really mellow and friendly when actually it was extremely competitive and isolating. So I rebelled." He became actively involved in the counter-culture movement.

During that time, David was also using marijuana heavily, and was hospitalized five times. He remembered,

> It was after I'd had a large amount, all five times I entered kind of an altered state for a few weeks at a time, or a few days. Who knows what pulled all that together. I really hate it when somebody says, 'Well, marijuana doesn't do that unless you have a predisposition to so-called mental illness.' I don't like the concept of mental illness but I think that all of those things played a role in entering whatever state it was that I was in which matches a so-called psychotic, schizophrenic state. A dozen psychiatrists diagnosed me that way and I ended up with the diagnosis, which I guess people at the DSM would see as somewhat accurate, of schizophreniform. . . Whatever I was entering, I experienced the classic things. The t.v. would be so-called sending me messages, or I'd look in the pattern of the door and see an angel there, read the Bible and I'd take it literally, immediately walking off into the south side of Boston to preach and entering into these spiritual states and getting in touch with a lot of buried junk with how I was raised, things about racism.

David said, "I certainly had problems, there was no doubt about it. . ." but he was even more disturbed by the treatment he received in the hospital.

> I really needed a place to be that would be supportive and help me with social skills and help me personally grow. When they said, 'You can go to Maclean [a psychiatric hospital outside of Boston],' well actually they told me I had to go [David smiled], my attitude was. . . 'Well gosh, this looks really great, it's like a country club, I'll be able to rest for a while.' But the moment I was there, it was this other world of extreme authoritarianism, control, and also not much peer support or human contact or appreciation about who I was. . . I was forcibly drugged, put into solitary confinement, and found that was pretty routine. . . I felt there were some valuable things that I was gaining from my experience and I felt that they were actually trying to wreck my spirit, my self confidence. . . . I reacted poorly to the neuroleptics the first time I had them. . . you'd try to do something, like make a long distance phone call, or make a list of books needed, and the more you tried to focus, the harder it got. By book number six, you're really pushing, then the harder you're straining, the harder it is.

David recalled that when he was in solitary confinement, he began "pounding on the screen, saying that I was going to do something to fight back against this kind of thing. Nobody had talked about it, that this Middle Ages kind of thing is happening routinely."

During his senior year at Harvard, a social service agency affiliated with the University referred him to a volunteer position with the "small and funky" Mental Patient's Liberation Front in Cambridge. David remembered, "It was just a little group of us, some people with severe problems, but I discovered that the system had really messed over some of these folks, like restraints, forced electroshock, just awful horrendous stuff." He has been involved in the Movement ever since then.

Sue

Sue Poole is a 46-year old woman who comes from a family of "white, upper-middle class people who left behind lives of poverty in the mountains of Southwest Virginia to become white collar workers, business owners, and military officers." She currently lives in North Carolina. This was the only interview not conducted face to face; I met Sue through America Online and e-mailed her the interview questions, which she responded to online.

Sue originally sought help from a psychiatrist for a sleep disorder, and was given nine diagnoses. She wrote, "The result was 24 years of stigma, 14 warehousings, 12 useless, irrelevant and debilitating drugs." After being hospitalized in 1978, she was forced to resign her teaching job, and stigma prevented her from being hired again as a teacher. She turned to journalism and worked as a reporter in a city news room for four years. During this time, she went to a psychiatrist for medication to help with severe bouts with insomnia, but was denied access to medication which would have prevented her sleep disorder. As a result of her insomnia, she became psychotic. She writes, "instead of the preventative [medication], I was given an anti-convulsant, a drug intended to prevent seizures. The side effects were bizarre. . . hallucinations, truculence and outbursts of anger, profound depression and loss of touch with reality." She was fired from her job on the newspaper and

> . . . the way back is closed to me because editors don't want a hallucinating reporter. . . my former friends and colleagues in that newsroom haven't got a clue. They don't understand that I was given a drug that CAUSED psychiatric symptoms. The general belief is that my behavior was a symptom of mental illness when it was, in fact, attributable to the side effects of a dangerous psychiatric drug.

Sue does not tell other people that she has been labeled mentally ill. "Disclosure in the Bible belt would lead to some very brief conversations indeed. People run the other way. . . To discuss the label is an act of social suicide. It is not safe to disclose to anyone ever."

Sue describes herself as "a survivor of psychiatric treatment. The sleep disorder was marginally troubling compared to the treatment. . . locked wards, restraints, condescension from staff and doctors, depersonalization, pejorative labels. Every hospitalization was a new trauma." Her involvement with the survivor movement comes through her prolific writings online. She may be moving to California soon to take on an advocacy position.

5.2 SOS MEMBERS/CONSUMER-ORIENTED

Carmen

Carmen Lee is a 60 year old woman who has spent over twenty years of her life in mental hospitals. The last six years of her life have been devoted to founding and running SOS. Carmen also has a severe hearing impairment and is constantly accompanied by her hearing dog, a small black poodle named Macky.

Carmen said, "I knew there was something wrong way back when, but you just had to be bizarre in those days when I was growing up to be labeled mentally ill, to go to a psychiatrist." Carmen grew up in San Francisco in what she describes as a "very rigid Catholic family." Her mother sold real estate and her father was a banker. She remembers her family as being "filled with rage." Her parents sent her to live with an aunt and uncle in the East Bay in what turned out to be a very abusive situation. Carmen did not know why her parents sent her there. "I hadn't done anything bad, hadn't gotten kicked out of schools, then. I had no idea. Then I ended up in boarding school, finished up there, and thought that if everybody was pretending, I'd be the best pretender of them all. I had looks, I had education. I went to college, became an airline stewardess, married Mr. Right, had darling Baby Right, and all the time I was in agony. When I was 24 and my daughter was 15 months old, I couldn't run anymore. . . I just started fading away. . . In retrospect, I don't know if it was catatonia so much as it was preserving my soul. . . I just slipped away into catatonia to save myself."

The first three years she was in the hospital, she said she was literally "in a ball." She was given electroshock therapy and at one point was scheduled to receive a pre-frontal lobotomy. She had a doctor who "tried everything "and finally he played piano music for her and she responded and began to play for him as well. After this she started to dress herself and engage in life, and was discharged. She was in and out of hospitals for many more years. Carmen says, "It's been a very crippling life. But I'm much better now. I feel that I enjoy certain things in life now. I have to be very careful of stress still, but I'm much better. I'm glad I came through the other side to help other people."

Carmen does not like any of the terms used in the movement. She said,

> "Consumer" seems to me that you can consume and never put out. I don't like that. "Client" is not bad, because you could be a legal

> client, or a jewelry store client, so I'm impartial. "Psychiatric survivor," I feel like that's from the pity pot. I don't like that, it's like I've survived a holocaust. . . I think all those terms indicate some hostility, except "client." I don't feel hostile. I would like people to think of myself as being very strong to have endured what I have endured. But instead they look at mental illness as a moral weakness or a faulty character.

John

John, a 42 year old African American, has been a member of SOS since 1989. He recently completed his Master's degree is rehabilitation counseling and is working at a social service agency in San Francisco. He lives in an apartment with roommates also in the mental health agency where he gets counseling.

John was born in San Francisco but grew up in East Palo Alto. His father is an engineer and his mother is a psychiatric nurse and a teacher. He remembers that "it was kind of funny because we always had the things we wanted but we lived in a community where it was always identified as 'bad.'. . . we had always heard that the schools we were going to were inferior and we weren't getting a good education." John talked about his life before "ending up in the mental health system" in 1980 with a diagnosis of schizophrenia:

> I had been an athlete and gotten a scholarship to college for football and I had gone to a university, graduated, and was in graduate school. . . That was part of my identity, being successful, which was a really big part of me until I ended up in the mental health system and all of those things that I had done just really didn't mean anything to me anymore.

John later got involved in the mental health system as an advocate and sat on the Commission on Disabilities, the sexual assault task force, and the Board of Directors of the Network of Mental Health Clients. He considers medications an important factor in his ability to stay out of the hospital.

John recently applied for a job with a mental health agency. He was initially told that "consumers were strongly encouraged to apply" but was not called back for an interview. He was told that the agency didn't think he could handle crisis intervention. John said,

> This decision was made by a lady who never met me, talked to me less than 10 minutes on the phone. . . San Mateo County doesn't know what to do with me because I'm a consumer with a professional degree. . . . But I have my own plan. If I was to allow them to define what my expectations were of myself, I wouldn't be where I am.

John uses the term "consumer" to describe himself.

> It's a pretty euphemistic term because a lot of people don't even know what you're talking about when you say consumer. . . Consumer can mean anything. I've never used psychiatric survivor, and I've never used ex-patient. I have a real funny thing about saying disabled, because the way I look at it, even though I know I have a psychiatric history, for what I need to do I don't consider it disabling. . . what is disabling is trying to hide it, always trying to hide that you've got something.

Ann

Ann, in her fifties, has been on SOS panels for the past several years. She was born in Mobile, Alabama and grew up on the Gulf Coast in an upper class family. Her father was in the advertising business and her mother was from a successful midwest dairy farm family. Ann was raised by a black nurse-maid until she was ten years old, and was quite aware of the stratified society in which she lived. She recalled that "Blacks were on the bottom, white trash was almost there and sometimes even below, and then the red-necks, the good old boys." At the age of ten, the family moved to Chicago. Ann attended a private Catholic girls' school, began modeling, and had aspirations of a career in theater.

She married at the age of twenty, mostly, she said, to get away from her mother. She and her husband moved to California and she had three sons by the time she was 24. Ann worked as a contract actress with several Hollywood studios, but her marriage was not as successful. "The marriage was doomed from the beginning, we were too young and didn't know ourselves, let alone each other." The family moved back to Chicago, and the relationship worsened as her husband had affairs. Ann made up her mind that "I wasn't going to spend the rest of my life living this way." She was determined to figure out a way to support her children and herself on her own.

After her divorce, she worked in acting jobs, soap operas, and public relations jobs. Ann laughed as she remembered her role as the “Treetop Lady” on a local television’s children’s show. She also got a degree in theater arts from Northwestern. In the entertainment industry social world in which she moved, she recalled, “You talk about sex, it never stopped. . . and this was the beginning of the sexual revolution.” She was also introduced to drug culture: “Everybody always had something—cocaine, phenobarbitols, marijuana.” Ann remembered working the nightshift at auto shows in order to work other jobs during the day. “That’s when I started getting really manic. I had symptoms of it in college, I started to get really hyper.” She took “speed” to keep her weight down and her energy high. “I thought I was superwoman, thought I could get by on little sleep, very little food, pop a couple of dexies, and be off and running.” At other times, she experienced severe depression: “I would go to bed and sometimes stay there for three weeks. They couldn’t figure out what was wrong with me so they decided I had bronchitis.” She sometimes experienced fugue states where she could not remember what she had done for several days. Friends suggested she should go see a doctor, but Ann said her level of activity and drive to support her children got her through. “I’d sort of muddle through and it would clear up, and I’d go on my merry way.”

Ann re-married and moved back to California. Although the early years of this marriage were good, her husband began making bad business deals and lost much of their money, and then had a long affair with her sister. Ann began drinking heavily, and developed multiple sclerosis. She said she started to get really “symptomatic” in 1986. Her first contact with mental health system was in 1988 after a serious overdose. She was hospitalized in in a critical care unit for a few days then in the primary care unit for almost a week. Though a psychiatrist interviewed her, she was discharged with no psychiatric follow up. She attended a two week program on drug and alcohol addiction and realized that she had tried to kill herself with pills and was drinking too much. But she found the program limiting: “I learned a lot about alcohol and drugs, but it didn’t address any of my problems.” She made another serious suicide attempt in 1990 and was hospitalized for a month in a psychiatric unit. Once again, she had no follow up on discharge with any counselor or psychologist. Ann said her mental state got even worse: “I couldn’t read, couldn’t focus, I was stuttering all the time.” At that point, Ann said, “I would have done anything. If you had told me to go stand on my head in the corner and whistle for fifteen minutes and I would feel better, I would have tried to do it." She started seeing a psychiatrist and also began to decrease her drinking.

When her second husband died last year, Ann was left with thousands of dollars of his debt, was unable to afford treatment, and was discontinued by her insurance company. She had to sell many of her possessions, and eventually had to apply for social security disability and Medi-Cal in order to continue to see her doctor. Ann identifies herself as a "consumer" and for the most part, feels that the treatment and medication she receives from her psychiatrist have helped to stabilize her moods and saved her life. She calls her psychiatrist "one of the good guys."

Jay

Jay McDonald 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 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. He 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. He said,

> When a person gets isolated somewhere because everybody else wants to be at the windows [in the office], 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 exacerbated Jay's sense of isolation, and he began to hear voices and feel suicidal. Jay 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 as a computer programmer.

Jay describes 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 felt 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."

Genett

Genett Mills is a 24 year old woman of Filipino and African American ethnicity. She became involved with SOS during the time that I was conducting fieldwork with the group. She also volunteers with The Community United Against Violence, an organization that fights hate crimes against the gay, lesbian, bisexual and transgendered community.

Genett grew up in San Diego in a "working class poor" family. Her mother came to the United States from the Phillipines at the age of 25. Her father was in the navy. She remembers seeing him only three times in her life. "When I was born, mom was basically all alone. My father wasn't there. He was out to sea, or if he was back he was in jail. She tried to raise us and work two jobs." Genett said she knew that

> there was something different about me when I was a little kid, around four or five years old, but when you're that age you don't know the name to it. . . Throughout my life, I was really anxious and panicky. I was afraid of doing anything throughout my whole school period. I did not talk unless I was called upon by my teachers and even then, I would pretend I didn't know the answer.

She later vacillated between feeling very good and very bad. "My mother would beat me out of bed when I was depressed, and then back into bed when I got manic." Genett described Filipino culture as having even more stigma toward mental illness than America and said her experience was "very shameful" for her mother. "To this day, she says, 'You didn't get it on my side of the family.' . . . She tries to keep her family as normal looking as possible."

When Genett was attending a junior college in San Diego, she saw a counselor at the health center, who only gave her a sheet listing the county's crisis line phone numbers. Genett moved to San Francisco and saw a psychologist. She said the experience was good, but she could not afford to see after getting laid off from a job. Genett's first hospitalization occurred while attending San Francisco State University. She said she got into trouble with the housing department because she was having manic episodes, "but at the time I didn't have the name for them. . . I was stressing [because] they were asking for money because rent was due and I was living off of my student loans and scholarships. But of course they don't wait for that." Genett lost a job because of another manic episode, and after a suicide attempt she went through a period of hospitalizations and homelessness. She said, "You just want to get off that rollercoaster, and sometimes you just can't find a way to stop it, not therapy, or meds. And so sometimes the only solution seems like suicide."

Genett does not use any of the terms I asked about. She said,

> I just view myself mainly as a person who happens to have a mental illness. . . I've taken a proactive stand about my health. That's why psychiatrists sometimes hate me. I really read into medications and side effects. I don't want to get into that because that's happened to me a couple of times before. So I think, I'm just a person who happens to have mental illness and I'm doing something about it.

6. THE GROUPS: NAPA AND SOS

6.1 NAPA

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 explained, the very notion of the "stigma" and efforts to combat it operate from the assumption that mental illness is a biomedical entity. 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:

> I reject this whole thing that it's okay and there is no stigma to being mentally ill, because I think not addressing the conformity issue is really serious. I think that's what it boils down to a lot. There needs to be room for us to be lots of different ways and have support to have a lot of different feelings and places we can have those and still have a good life.

In its current form, the membership consists of approximately 12 people. Of those, about half are active in coming to meetings and attending events. NAPA is officially incorporated as a non-profit organization which has officers because of incorporation paperwork, but in practice, the group is very loosely structured and no one has a title. NAPA meets irregularly in a space provided at the Berkeley Drop-In Center. Membership is inclusive and open to anyone who agrees with their goal to end psychiatric oppression. Most members identify as survivors, but some psychiatrists and other doctors have participated in past meetings and actions.

Activities during the past few years have included staging protests at the American Psychiatric Association convention and at hospitals in the Bay Area which use electroshock treatments.

I attended two NAPA planning meetings and two "presences" against electroshock held at Alta Bates Hospital in Berkeley. I asked one of the members about the choice of the word "presence." He said, "We didn't want to call it a protest or demonstration because if only six people showed up, we'd feel like it was a flop."

One meeting was attended by seven people, the other by four. The meetings were loosely structured, beginning with an agenda but often wandering far away from the items on it. Because the organization was in the process of re-starting after several years of inactivity, there were business matters to be addressed such as investigating not-for-profit status and opening a bank account. But these discussions bogged down and it was clear that the real "juice" for people was in planning actions. One man said, "I'm much more interested in going to protests on the street than in meetings, so let's pick a day!" Ava picked up on this energy, "We are having a presence before we have another meeting. Ban meetings now!"

The first presence was scheduled for February 13, 1996. As part of my fieldwork and out of my desire to lend support to the group, I asked if I could attend, and was welcomed. Five people showed up at the presence—three NAPA members, Ava's girlfriend, and myself. We all stood on the sidewalk in front of the main entrance at Alta Bates holding signs that read, "Shock Kills," "Stop Shock Now." We handed out information flyers which Ava had made, and also had a NAPA mailing list and a petition against ECT from the Support Coalition International. Hospital security came once and told us to move, but nothing happened so we stayed there for about two more hours.

While many people shook their heads and walked away when we asked if they would like a flyer, there were also many who spent time talking with Kris and Ava about ECT. Many were surprised to find out that ECT was still being used. One man said his 14-year old niece was "locked up" in Herrick Hospital and he wondered if she might be given ECT. Ava said it could happen, and she told him to be aware that it affected brain development. Doctors and nurses were part of the passing crowd, and some of them stopped to talk. One nurse told about being present when ECT was administered and how it disturbed her, and also how the doctors would leave the room until it was over.

I asked Kris what outcome the group would like to see from the presence. She said they did not yet have a long-term plan; the purpose of this presence was more to mobilize NAPA into activism and increase awareness that ECT is being administered and to educate the public about its effects. All NAPA members were pleased with the results of this presence, and Kris said, "It feels great to be out here."

While NAPA is an independent organization, it is also affiliated with the Support Coalition International (SCI), a network of over 40 groups around the world who share the goal of speaking out against human rights violations in psychiatry. SCI groups tend to be more survivor-oriented and represent a wide range of activities, from drop-in centers, to street level groups which do outreach to people in crisis, to groups like NAPA which conduct political activism.

Within this larger survivor movement of which NAPA is a part, the strategic emphasis is on avoiding theoretical debates and instead focusing on human rights issues. David Oaks said:

> . . . we don't get caught up in Jungian or spiritual emergence or Freudian psychotherapy, and that's where a lot of people who are leaders in our society are at, they're all debating all these theories. What we're saying is we're focusing on specific human rights concerns, and this other stuff may be okay to do, but we need to do the humans rights concerns. It's strategically reaching some amount of change, it challenges the way things are.

David talked about ADAPT, a radical group in the Disability Rights Movement, which he saw as parallel to survivor groups. ADAPT members would go in their wheelchairs and tie themselves in front of nursing homes to protest the way Medicaid money is distributed. As David said, the scene of people in wheelchairs, fists raised in the air, chanting, made for "some amazing visuals, and it's difficult to arrest them, get them into the cars . . ." The group demanded that Medicaid devote 25% of its nursing home budget to at-home attendant care. David said:

> That's a nice simple demand, but you see the difference between that and the classic liberal demand. The classic liberal demand is "We need to protect Medicare/Medicaid funding." Period. End of Story. That is bankrupt. That doesn't work. What's missing is a radical analysis or a green analysis.

One of the movement's strategies to be more effective in influencing social change and public policy is to build bridges with other activist groups including the womens, homeless, African-American civil rights, disability, and gay/lesbian movements. David recalled, "In San Francisco when we did our protest [at the American Psychiatric Association convention], Transgendered Nation gave us the most direct support. . . . One of our groups is the Fruit and Nut Bar, and they marched in the Stonewall protest."

The main medium of communication for the movement is *The Dendron* newsletter. The publication's logo is a brain with wings on it, and inside the choice of the newsletter's name is explained:

> What is a dendron? It means "tree" in Greek. Your brain, under a microscope, looks like a wild ancient forest, with tree-like dendrites networking billions of neurons. Psychiatry is like modern forestry—clearcutting brains to prop up the current failing, dominating system.

The Dendron and an internet mailing list called "HealNorm" both serve to alert survivors and consumers about human rights violations.

According to David the main issues the groups in SCI (including NAPA) are currently working on are forced electroshock, racism in psychiatry (specifically the Violence Initiative[*]), and the Heal Normality campaign. These come from both a grass-roots level, with local groups writing to *The Dendron* about relevant issues, and from the SCI organizers (including David) who notify members about important issues and pending legislation.

6.2 SOS

SOS takes an educational approach to activism. The group has given over 400 presentations to a variety of groups, including civic clubs, colleges, nursing and psychology classes, hospitals, high schools, and local radio and television talk shows. According to the SOS brochure and Carmen, 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. They particularly focus on the perception that people with mental illness are dangerous. The group also advocates for improved treatment, fights against budget cuts to mental health services, and provides consultation to employers with questions about how to apply the Americans with Disability Act in the work place for people with psychiatric disabilities.

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[*] This is a federal initiative funded by the National Science Foundation, the Justice Department, and the Centers for Disease Control which focuses on biological and genetic factors in violent crime. Proposed treatments would involve forced drugging, and research designs would call for psychologists to identify young children who could be candidates for drug treatment. Some programs would target children who are inattentive or disruptive in grade school.

The membership of SOS is fluid; Carmen's title is "chair," and there is a pool of about twenty people who volunteer to form a speaker's panel for each presentation. Though the group has no regular meetings, members always go out for a meal together either before or after a speaking engagement, and they also maintain contact with each other between presentations.

SOS maintains autonomy by being composed of only consumers, who make all group decisions. The San Mateo County mental health system provides some support by letting SOS use county vans for transportation to presentations. SOS funding comes entirely from donations and grants.

In the course of fieldwork, I attended seven SOS presentations. Typically, Carmen is contacted by an agency and asked to bring in speakers. She then makes phone calls to find five or six people who want to "do an SOS." In order to best address the needs of the audience, she forms the panel according to the group; for example, for the Suicide Prevention Center, she asks those who have attempted suicide and/or used the hotline. The format was the same for every SOS presentation I attended. Carmen would introduce the group, give a brief history of SOS, and then each person on the panel had five to ten minutes to speak. All speakers began by stating their name and their psychiatric diagnosis, and then gave a brief history of their experience with mental illness and involvement with the mental health system and other agencies. After speaking, time was set aside for questions, answers, and dialogue with the audience. At the end of the presentation, the audience was asked to fill out an evaluation form.

Carmen feels that it is important at the SOS panels to be "very constructive and not blame the system, because everybody has their own way of getting well." Comments about the mental health system by SOS members tend to be restricted to individual doctors or other professionals, usually unnamed, who in some way treated them as less than human. Ellen, an SOS member whom I did not interview but who participated in panels I attended, told a story about being interviewed by a nurse during her first admission to a psychiatric hospital. When the nurse asked if she had a college degree, Ellen said that she had a Master's in criminology and had previously worked at the White House as a tour guide. This was true, but the nurse refused to believe it and instead noted it as a delusion.

Members also related stories of discrimination from other systems. Sharon talked about a counselor at her college who discouraged her from applying to graduate schools because she was mentally ill. She was told, "Nobody will take you." Sam, who has post-traumatic stress disorder as a result of spending the first six years of his life in a concentration camp in Austria, told a story about being picked up by the police when he in a dissociative state. They threw him in jail under a charge of drunk and disorderly conduct.

In the interactions between the audience and the SOS speakers, some audience questions were notable for their assumptions about normality and mental illness. One woman asked, "Do you ever feel happy?" Another said, "I'm shocked. You guys are blowing me away—you're so articulate!" One woman looked at Genett and said, "I have a question for the bi-polar on the end. How long do episodes last and do you ever feel normal?" Genett did not directly confront this remark during the panel, but afterwards when I asked her how she felt about being described as "the bi-polar on the end," she shrugged and laughed, indicating it happened a lot. Sharon was amazed that after the SOS when she had talked about her college counselor discouraging her from applying for graduate school, not one person in the audience commented about that incident in the question session or on the evaluation form. She felt she had shared her anger about an injustice and no one had really heard it.

Sometimes, the presentations created openings for audience members to share their own experiences with illness and stigma. One woman said, "I was on lithium [a drug used to treat manic-depression]. The terror of being separate. . . nobody can understand what you're talking about. They see you function, but they don't understand what's going on." Ann told me that sometimes she thinks that SOS audiences are being "too polite" and not saying what they really think about mental illness for fear of being offensive. When I asked her what she thought they might say if given permission to be "politically incorrect," she thought the panel would hear comments such as, "I'm afraid of the mentally ill, they are violent, they smell."

An important part of every SOS was the ritual of going out to a restaurant either before or after a presentation. We brought along Macky, a small black poodle who was Carmen's hearing dog. These meals were lively gatherings and ways for SOS members to catch up with each other on events in their lives. Many of them knew each other from either prior SOS events or from common involvement in mental health agencies. Those who were new were warmly welcomed and asked many questions. During these meals, I watched another way that SOS members practiced resistance—loud and animated conversations about medications, good doctors and bad doctors, hallucinations, and other consequences of their lives. While I became a little worried for them and wondered what diners at adjoining tables would think about these discussions on what is usually a taboo subject in a public place, no one in the group seemed to care. I was confronted with my own mentalism and discomfort with difference.

7. STRATEGIES OF RESISTANCE

THE BLIND GENTLEMAN

Part of my work with Joe was to help him find a place to live. We had to do this frequently, usually every four to five months. There was always something not quite right about the living arrangements we could come up with: Joe would begin staying up at all hours of the night, flush things down the toilet, and in general drive his roommates crazy, so to speak. Or he would live alone and become fearful for his life, believing that there were people trying to get into his room at night, or leaving strange items in his refrigerator. These fears were not necessarily unfounded; the drug-using crowd that Joe hung out with was not beyond doing these things.

During one of our apartment hunts, I helped Joe get the classified section of the local paper and had him circle apartments that were in his price range and sounded interesting. His choice of places was considerably improved this time because after three long years, Joe had finally arrived at the top of the waiting list for a valuable Section 8 certificate. These certificates, issued by the Housing and Urban Development Department, enabled low-income and disabled people to have two-thirds of their rent subsidized by the government. We got the phone set up in my office and Joe started calling landlords. I sat by and listened.

"Hello, sir. I am calling about the apartment listed in the paper."

Silence.

"I have a Section 8 certificate and I am a blind gentleman. May I and my caseworker come see the apartment?"

My jaw dropped and I looked at Joe, because he was not blind. At times, Joe would make comments about being blind because he wore very thick glasses which were essential to his sight. However, he could see perfectly well with his glasses. I was more bemused than anything else, because I knew that he was genuinely sincere in that comment.

Later I realized that Joe was strategically replacing one disability label with another, knowing that blindness carries far less stigma than mental illness. His strategy of blindness was operating at some deeper level than conscious lying—he had actually incorporated it into his own belief system in a way that psychiatry might label "delusional." And yet this was an extremely useful "delusion," one that protected him at least somewhat from the social stigma of mental illness, and would also explain my presence as a "caseworker" tagging along with him to look at the apartment.

The resistance strategies used by both consumers and survivors are many, and often, quite creative. In the personal stories presented in a previous chapter, the first elements of resistance are evident: Ava refusing to see the psychiatrist her parents had chosen for her; Genett taking a "proactive stand" about her treatment. I found these strategies clustering under several different themes.

7.1 Madness as Resistance

In some cases, the "illness" itself could be seen as a form of resistance against society and patterns of socialization. Others have noted this strategy among people in positions of lesser power; referring to everyday forms of peasant resistance, Scott wrote, "Physical distress and illness can also be thought of as acts of refusal or of mockery, a form of protest (albeit often unconscious) against oppressive social roles and ideologies" (in Lock & Scheper-Hughes 1990:70).

This seemed to be especially true for the women with whom I spoke. Carmen said:

> If I had had a normal life I think I would have been a high achiever. In those days, the only thing that was open to a woman that was respectable for adventure was being an airline stewardess. Or secretary or teacher. I would not have chosen to be either. I probably would have gone into social law. But I would have been considered a weirdo back then.

She talked about spending years "pretending" that she was okay, and then,

> I just slipped away into catatonia to save myself. They had a body, there are a lot of bodies, but they didn't have me. I think in looking back, I think that's why I, unwillingly of course, did that. I knew there was something better and I needed to reach it. That's a heck of a way to do it.

When I pointed out to Carmen that she is practicing a kind of social law now with the founding and running of SOS, she agreed and said, "It's great, it's funny, ironic. I wouldn't have been happy being a mediocre person, being a commonplace person. I wouldn't have been happy just being a homebound individual." Her experience with mental illness gave her a second chance to do something out of the normal expectations for women from her era.

Ava felt that some of the doctors and mental health professionals who worked with her viewed her outspokeness and feminist politics as part of her illness. She equated their attitude toward her with oppressive treatment directed at women:

> They didn’t look at me as an incest survivor. I was some nutty woman who had created a story of what had happened in her life so that I could be a victim, so that I could get attention. . . [They told me] I had something biological wrong with me, and this would cure it, this would “fix” me, just like a clitectomy. “You got a little too much, let’s cut it off.”

7.2 Passing and Coming Out

A crucial point in the experience of madness is when and how people decide to disclose their status of having been defined “mentally ill.” In a parallel to the experience of gays and lesbians, the people I spoke with frequently used terms like “coming out” and “passing” to describe this process.

Coming out itself can be a main resistance strategy, as exemplified by Kris, who saw it as her way of subverting the labeling process:

> I think one of my best protections is being proud. If I go to school and get my master's in psychology and work at an internship and really say, "I've been locked up, I've had electroshock and it sucks. Be careful with these labels. I don't like them and I don't find them useful and I hate the DSM." There are a lot of mental health professionals that do hate that book and disagree with most of it. That takes a little bit of the power out of it. I'm not quite as vulnerable to being labeled. I'm not hiding anything.

“Passing” can mean safety, but the consequences can also be negative and can also affect one’s mental health. Carmen noted that covering up is “very lonely. It makes the illness perpetuate. . . I think it keeps your illness going much longer because your energy just goes to that. You lose who you are more easily. It keeps barriers between people.” Kris said she learned “. . . how to look good and pass. I think that is a direct result of the hurt. One of the things I did after the hospitalization was get two waitress jobs and try and show how competent I was. That's a skill that I have that is kind of a protection.”

In making the decision to come out, people weigh the risks and the benefits, and the power relationships they have with those to whom they will disclose their experiences. Job and interview situations were seen as particularly risky for coming out. John talked about a job interview when the supervisor offered him a position.

> She asked me if I had a disability. In employment, you're not supposed to ask that question until you offer somebody a job, then you can ask them. I looked her right in the face and I said no, I don't have a disability. I got a very good evaluation at the end. But I just wonder if I told her that I had a diagnosis of paranoid schizophrenia how that would have changed the dynamics of how we work together.

Genett said, "I think the times that I do hide it are when I feel that I'm talking to a person who is a threat to anything vital, like a career, or my lifestyle, or anything like that."

There are definite risks to coming out, but overall people identified it as a process that empowered them both psychologically and politically. Jay related a pivotal incident for him during a job interview:

> You get to the point in the interview, "Tell us more about yourself. What about this ten year gap?" At that time I was kind of sick about trying to figure out what to say. "I was on vacation. . . I had a long operation." Right on the spot I decided to tell them the truth. It was scary as hell, and I think I started crying in the middle of it because of the tension, and they just sat there. I thought they were thinking, "Oh god, we can't hire this guy." But apparently they were impressed because of all the volunteer work I'd been doing. . . I got hired, and I worked there a year and a half, and everything was fine. It surprised the hell out of me when they actually hired me. You're always told, "Don't tell anybody, there's a lot of prejudice out there. It's your choice, but take it with a grain of salt and think about it first." It was great. . . . You get to the point where you are so worried about everything that it's a relief to actually say it to somebody no matter what happens.

John remembered,

> . . . when I was in graduate school, I disclosed to my class that I had an illness right toward the end. I disclosed a lot of other things, there was lot of crying, people cried, I cried the most. It was like I had kept it all in, years of keeping that all inside. . . . The reason I had kept it a secret is because I thought they were going to treat me different. But they haven't. They're still my friends. . . . I thought I would be stigmatized, wouldn't be treated the same way. I don't know if that's unhealthy for me to think like that, but that's disabling for me.

Coming out in large numbers can even have political implications. David noted that this was a way to subvert the psychiatric diagnostic process:

> They actually have debates in the APA journals about what is a bizarre delusion, because to be psychotic you have to have a bizarre delusion. So it's that nobody else shares your belief. For instance, UFO abduction cannot technically be a bizarre delusion anymore. . . . It shows you the power of organizing. Say you have two people saying the same thing, then they label it as a cult. But they technically can't label it as a delusion any more.

7.3 Joining A Group

As an extension of coming out on a personal level, at a certain point the people in this study decided to join their voices to others with a shared experience. They joined groups, and in some cases, started their own group. What led them to make that choice?

Many times, it was a refusal to be controlled and stay silent any more. Carmen said that she and several others founded SOS because:

> . . . we were sick and tired of being sick and tired, and ashamed and controlled. People were taking control of our lives. To the system, we were good for nothing. We didn't have any lobbyists at the state level, we didn't have any lobbyists for anything. So we just took it upon ourselves, not to so much be lobbyists as to try and break down the barriers of prejudice so that other avenues could open up to us. . . .

Genett decided to join SOS because, "I just got sick and tired of shutting up because I'd been quiet all my life, and everybody told me to shut up and be quiet. I was always scared of saying anything. I decided it was time to put my anger and my frustration into something positive and that's what I did."

Sometimes the reasons were very personal. Carmen said, "I'm doing this also for my brother, the one who killed himself. If he had more support in the world he wouldn't have done that. So I do it partly for him, partly for me, partly for the people coming behind me. It just feels very right, what we are doing."

Sometimes the decision to become more of an activist came after a period of preparation. Kris said that for her to get to the point where she was ready to speak out took "years and years of healing." She went through feminist therapy and then got involved in co-counseling. A few years ago, she attended hearings on electroshock in Berkeley and then became involved with NAPA. Kris said,

> I hand drew pictures and signs that said, 'No electroshock,' and passed these things out and invited people to my home, then asked them to tell their stories. I met people at the hearings and invited them to my home for pot lucks. These were strangers! It was taking a risk, taking on leadership, trusting that people are okay.

Kris also noted that she had to be in a different social role to feel like she had the "right" to speak out.

> This is all about class, really. When I went back to school, my self-esteem rose to the point where I really wanted to speak out about this stuff. Suddenly, I was the person who had a right to speak because I had a State fellowship, my way was being paid to college, it was competitive and I must be good, I got this fellowship. . . . It was almost like, "Now that I have a certain amount of credibility, class-wise, or professionally, or whatever, then I can talk about this stuff and be angry about it and maybe someone will listen to me."

Sometimes the decision to join a group came from a need to reach out to other people and share an experience that had been kept secret. John said he got involved in SOS ". . . because I felt like I wasn't getting out enough and meeting people. Now I have some pretty lofty goals for myself that have evolved, but it started back then that I just wanted to get out and be busy and meet people." Jay said when he met Carmen and heard about SOS he thought, "'Wow! I can talk about this. People understand, they've been through the pain. They know something about the kind of pain you go through.' For a while I just took on the label, 'God, I love this!!' I could talk about it."

Sometimes people happened upon the movement just by chance, not really knowing what it was about. Ava said,

> I don't know that I was ready to speak out about it, I think I just did. It wasn't a conscious thing. I first went to the group [NAPA] thinking it would be more like a therapy group. . . . But then when I realized it was a political group, that was great. I just started doing it.

7.4 Manipulation

What appears to be cooperation with "the system" can at times be a very effective resistance strategy. Leonard said he figured out that the way for him to get out of the hospital, ". . . 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" (Farber 1994). David, when forced to take Haldol (a psychotropic medication), said:

> I resisted it for a long time, and then on t.v. they had the film *Terminal Man*, and there was the brain operation sequence and I was watching that, and I agreed to take the Haldol as almost like an anti-sacrament, to fight back against whoever was giving me such a terrible nerve toxin.

The long-term results of this cooperation, in both Leonard's and David's case, turned out to be quite subversive. They were able to see these strategies as a way of getting discharged from the hospital without internalizing notions of "mental illness" into their lives.

Consumers also use this strategy as a way to get treatment they feel is effective and desirable, but may be denied to them. Gloria, an SOS member, talked about needing treatment which was denied to her because she was not deemed "sick enough" by her insurance. She said her doctor, whom she feels has worked very well for her, had to embellish facts about her psychiatric history in order for the company to pay for continued treatment. She admitted that at one time in her life she really had driven a car off of a highway ramp, but now her doctor has her "crashing into a wall at 100 miles an hour." Gloria laughed and said that if she really did all the things she is reported to have done she would be "locked up for life." But she also worried that if she appeared to be getting too "well" she would no longer be able to receive therapy and medications and would indeed get worse.

7.5 Direct Encounters With Professionals and the Public

Both SOS and NAPA use forms of direct encounters with the general public and the medical profession as an avenue for resistance.

In its over 400 speaker panels, SOS has reached, by Carmen's estimates, over 12,000 people who otherwise may never have had a substantial interaction with someone called mentally ill. One psychology intern commented, "This has been an invaluable experience. We never get a chance to hear what it's like to live with a mental illness. We hear it in therapy sessions, but it's different."

At the second NAPA presence I attended, there was a particularly powerful encounter between Ava and one of the anesthesiologists who drugged her before the ECT she had received three years before. At first, she did not recognize him. She gave him a flyer and they began to talk. He asked her how she was doing in the aftermath of her treatment and Ava said, "Really shitty, actually." She still didn't realize who he was, but when she asked him what he did at the hospital and he replied that he was an anaestheologist for ECT, the painful realization set in.

Ava described what she felt at that moment. "I was in shock. It was incredibly emotionally upsetting. I started having body memories rushing through my body, shaking inside, shaking outside." She told him, "You're the person I dream about every night and have nightmares about. I have a painting of you." He wondered if it was him personally, if he had done something different than the other anesthesiologists that she would remember him. Ava said, "It's all of you. Why did you do it? Did you just not know, or what?" Ava continued to describe to him the damage she had experienced from the ECT, and the part he, as the attending anesthesiologist, had played in it. He listened, and Ava said she felt like he finally "really got" what his participation was. Ava asked him, "What do the psychiatrists tell you [about people after they get ECT]?" He said that they are only told that patients are sick and that ECT cures them.

During this incident, Ava got support from the other NAPA members. One of them held her. Ava said that at first, the experience was "incredibly painful. . . I wanted to hit him really badly. Incredible rage, but I put that under control, and then I was just feeling incredible pain, deep intense pain and terror." At the end of their encounter, the anesthesiologist took a handful of flyers and said that he would talk to the doctor who had prescribed the ECT sessions. Ava reached out and shook his hand. She said, "It was an incredibly healing experience. Very painful, but it sounded like he really listened and wanted to share that, and share what happened to me with other people. I felt healing in the sense of sharing my experience with him, who deliberately had a role in abusing me."

7.6 Humor

Humor was a weapon in the resistance arsenal of both survivors and consumers. One common strategy was taking psychiatric terms and turning them around. This effectively deflates their power. One day Carmen called me on the phone to excitedly tell me that the FBI was going to fly her to New York to take part in a conference. She said, "Sounds like a delusion, doesn't it!!" In our interview, at one point Carmen raised her voice at her dog and then laughed and said into my tape recorder, "They'll think I'm being violent!" In a parody of the *The Diagnostic and Statistical Manual* (used by social service professionals to diagnosis patients), one issue of*The Dendron* contained a guide to diagnosing "professional disorders." (See next page.)

SOS panels also had many elements of humor. At the start of one talk, Sharon yelled out to the big auditorium audience at San Jose State University to ask what class they were in. When someone called out, "Abnormal Psychology," she said, "Well great, 'cause I'm abnormal myself!" Ann told a story about coming to consciousness after a suicide attempt, waking up in the hospital to see a psychiatrist that she found particularly incompetent, and thinking that she had died and gone to hell.

The Heal Normality campaign is another example of humor as a resistance tool. The campaign consists of posters and buttons which point out the "ten warning signs of normality." (See poster on next page.) Some of these signs 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*.' "(*Dendron*, Spring 1995:8). David writes 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.

7.7 Re-Definition

Sometimes resistance came through re-defining the experience as something other than pathological. Many people I talked to resisted, either in full or in part, the medical interpretation that their experience was simply mental illness. This was true for both consumers and survivors. Some people thought of the experience as a signal to make, or be forced to make, dramatic changes in their life. Leonard said,

> I think that maybe depression has a social and personal function. Maybe depression is the way that the organism has of alerting itself to the fact that the individual within that organism is not conducting his or her life in quite a proper, correct, ethical, practical manner and that there should be a change. . . . Maybe you don't have any sense of purpose in your life. Maybe that's a signal to you that you need to get it together and the only way you can do that really is by looking at yourself, by becoming introspective, by gaining more knowledge about yourself.

On a similar line, Ava said, "When people are not depressed, it is quite often a sign that they are out of touch with what's really going on within themselves and outside themselves."

Carmen said,

> I think that mental illness is a sign, just like a bad backache or headache, that there is something you need to know about yourself. In my instance, I think I needed to be in touch with the spirit within me, the intangible spirit. Whether you want to call it God or goodness, whatever, that part of me that I was never able to get in touch with. So I think that the mental illness, and I never thought I'd ever say this, has actually been a blessing to some degree.

Several talked about a spiritual component in their experiences. Carmen described her journey into catatonia as a way of "preserving the soul." NAPA members more often than SOS members put the experience in this spiritual context and saw it as the psyche's natural way of healing. They felt that most medical interventions stifled that process. Kris said,

> A lot of what is considered pathological is people figuring out their own healing. That's what I believe, that people with support, they shouldn't just be left alone out in the desert, but with loving support, will heal themselves. I really do believe that, and that people are moving toward healing, naturally. They are trying to sort it out. They are trying to heal from some really heavy duty hurts. A lot of interventions that come from the mental health system just completely put a lid on that healing process. There is often a real reason why someone is flipping out in whatever way they are doing, and that might need to happen, and for a person to not function and lose control. But health is defined as being in control and 'functioning.' I don't think it's really possible to be full human beings, with a wide range of emotions, and always be doing that.

Leonard said,

> For most people, it [madness] would be clearly seen as a medical and psychiatric problem. I see it as a political and social problem. And also a spiritual problem. I think a lot of people who get locked up in psychiatric institutions have just begun to undergo some spiritual changes in their lives. They have begun the transformation process, a process which I think humanity is going to have to undergo, both individually and collectively in order to survive.

Unlike survivors, consumers were more apt to apply the term "mental illness" to themselves. Even so, I observed that they were trying to expand the possibility of what that could mean. Consumers were usually comfortable seeking assistance within the mental health system, but resisted perceptions that narrowed the scope of their experience. At an SOS panel given to a suicide prevention center, one of the women spoke about how she sometimes cut and mutilated herself. She said other people might label that "sick," but for her, it was a way to relieve her pain and "feel something." Another woman related that her overdose and close brush with death through a suicide attempt was a way for her to feel alive. Another SOS panelist nodded his head. There was a group consensus that these symptoms had the potential to be more than simply an indication of illness.

7.8 Choosing a Survivor and/or Consumer Identity

What accounts for the differences in people choosing to align with a more consumer or survivor-oriented approach to speaking out? Within the small group of people whom I interviewed, age, class, and/or gender did not seem to be factors as both groups were diverse in these areas. One clue is in the way their identity was shaped as a result of being hospitalized or treated for a mental illness. Every survivor I talked with had what he or she felt was a horrible experience with the mental health system, which included incidents of forced drugging, electroshock, hospitalization, and solitary confinement. Consumers, even if they had isolated complaints, tended to feel more satisfied with their treatments and derived benefit from either medications or therapy obtained through the mental health system. They did not want to lose the option to have these treatments.

Several consumers mentioned that there was a certain point in their lives when they felt a shift in their identity, from thinking of themselves as people who were having problems or difficulties, to taking on the label of mental illness. This shift had nuances of being both helpful and limiting. Some consumers felt relief when they realized that their "problem" had a medical diagnosis, and that treatment seemed to help alleviate it. But their words also conveyed ambivalence about having to be placed in a category to get to this relief. Jay said,

> . . .until the last four and a half years, I lived as one of the "normal" people out there. I wasn't in the system, I didn't know anything about the system, I didn't know anything about mental illness, I was just as much afraid of it as anybody else. And all of the sudden, I am mentally ill, or I find out that the descriptions of what's going

> on fit my life closely enough that that's pretty much what it has to be, and the medications make a difference so obviously there was a biochemical problem somewhere. . . .

John said, "When I really knew I was in the mental health system, when I was a consumer, was when I ended up in a halfway house." Before that, he said, "I had no idea what the mental health system was. I had no identity with it. I knew I was struggling and I was having a difficult time. I was suicidal, I even had three attempts. But before then I just thought I was a person who was having a lot of problems."

This shift did not happen, or took a very different twist, for survivors. Even though they acknowledged their difference from "normality" and, in some cases, their suffering , they refused to be labeled. Kris said, "I rejected it from the get go. . . I stayed out of the system. Once I was out, I really stayed out. Except for feminist therapy and some real mild therapy. I never took drugs. I was never in a halfway house. Maybe I should have been, I was weird!"

This refusal is not without some ambivalence, however. Ava said that she both internalized and resisted her diagnosis at the time it was given. She still sometimes tells people that she used to have a "borderline personality." When they tell her, "You're not borderline, you're ex-girlfriend is borderline," she finds herself ". . .trying to insist that people don't know that I really was crazy. . . . There's a part of me that still buys into it. There is a part of me that's internalized it."

Several factors seemed to play a part in how survivors positively integrated the experience of madness into their lives. Sometimes it was a matter of knowing that options for other explanations existed, as in the case of Kris' memory of meeting Leonard. She used this memory to help her hold onto an alternate interpretation of her experience, one which eventually led her to become involved in activism and the survivor movement.

Sometimes it was another person who validated that person's sense of differentness as not pathological, perhaps even as a gift. Ava related a story that she felt was an important reminder to her about the value of being "different." She was taking the train to see her family one Christmas and remembered:

> I was standing at the Amtrak. I was all dressed up in a black gown and a black hat, a black lace thing covering the black gown, and combat boots. I had my big huge backpack and a big bag of 27 Christmas presents. This man comes up to me. He was such a trip. He looked right at me and he goes, [Ava imitates a thick European accent] "People are looking at you. People are staring at you. But they don't understand. You have a design for living! You have a design for life! Change for no one! Are you from the old country?" [Ava laughs] That was the beginning of my trip.

Leonard explained why he thought he was led to reject a pathological interpretation of his experience:

> A lot of it had to do with where I was before I was locked up. I had gone through considerable personal change in terms of my beliefs and lifestyle. I was evolving, I felt, into a much more complete, wholesome, idealistic, and still practical individual. . . . [My family] thought that there had to be something drastically wrong with me that I was giving up this world that they thought was so wonderful, because they were upper middle-class people who were very content with society. When I became more aware, and to a degree more enlightened, I began to see that this society isn't all that it's cracked up to be.

Sometimes the ability to resist the label came from a deep place within the person. Ava said,

> How did I get that it was bullshit? I think I know because of my core inside that is my spirit, that is who I am, that is my strength, that they couldn't touch, that no one has touched, that no matter what has been done to me has held on and said, "I am I, I am this. I'm not these labels. I'm not what you call me. I'm who I am."

She also remembered telling herself when she was a little girl, "Never forget who you are, never forget where you came from." Ava said, "I was remembering before I was born. I was remembering the energy all being connected together, strength, power, love, all of that. I was telling myself that when I was a child to never forget that was important." Ava also tapped into her creative powers, especially music, to reinforce these memories of her self-identity as distinct from the labels given to her:

> . . . ever since I was a little girl, I used to tape record myself and tell myself who I was. I have tapes going back to when I was a little kid talking about who I was, and singing, and making up songs. Music played an incredible part. I found a tape recently, after the shock, singing this really angry song called "Nothing happened." Like being my parents' voice, "Nothing happened to you." And about how I knew what did happen. Music is my anchor, my number one anchor. When I sing the best is when I let myself be a conduit to that power that is within me and also way bigger than me.

She also considers traveling to other countries when she was a child as another source of knowledge that "this culture is really one way of doing things and looking at things. I think that helped me a lot . . . in understanding that it wasn't about me."

In their personal definitions of mental health and illness, survivors and consumers tend to locate responsibility for the experience of madness in different places. Survivors, either initially or through a pivotal incident, located the locus of control for their experiences not solely within themselves but as a part of the society around them. Ava said,

> . . . the term mental health implies in some way that there is such a thing as illness, which I don't believe in. . . I think that when somebody has what is called an "illness," it's a reflection of what's occuring in society at large. Our tendency in society is to pathologize individuals as opposed to looking at the system as a whole. . . . I feel the people who are most in touch with their feelings and emotions are quite often the people who end up getting labeled mentally ill and end up in the system. . . I believe most typically those are the people who are the healthiest, because we are in touch with our feelings, and in touch with reality. And reality is painful.

Sue wrote,

> I define mental illness as abuse of power without conscience about the consequences of one's actions. . . . as the notion that people must conform to arbitrary standards of behavior or socioeconomic

> position to be worthwhile human beings. . . . as the tendency to think in terms of traditions as inviolable and infallible.

Perhaps the key to Leonard's philosophy and resistance is that, in his view, even an accurate assessment that someone is a danger to themselves is not a reason to take away their rights:

> Even if you could be certain that a person was going to commit suicide, that doesn't give you. . . or anyone else the right to intervene to stop that person from committing suicide. That also is a human right.

In contrast, consumers locate the control within their own body and mind. Carmen said,

> I define being mentally incapacitated when I can't work, not because society says I can't or I should, but when I can't work and control my life as much as I want to. . . To me that's illness. When you can't take care of your own needs. That's my only definition between mentally healthy and mentally ill. . . . That's how I define it, and why I feel I have been somehow crippled. Mental health would be being in control of my life.

At times, survivors had strong resistance to even using the words "mental illness," and gave personal definitions only after making it clear that they were defining the construct on their terms. When I asked Leonard how he would define mental illness and mental health, he said,

> I'm just not into that model at all. What used to be called good and evil is a rough approximation of what we now call mental health and mental illness. Back in the Middle Ages, the people who did the things that get labeled as signs of mental illness would be said to be doing acts of evil. Mental illness is a conglomeration of ideas and practices of individuals who are outsiders, people who don't fit it, who cannot fit in or will not fit in. . . I would abandon the very dichotomy itself. It's not a disease, in any sense of the word. It's just a pattern of thought and conduct that is unacceptable to mainstream society.

Kris said,

> I don't think I'd call it mental illness. I'd say people have crisis, and that might be normal. And there might be people that will never fit in, that might be real different from most people. Lots of communities and places have accepted eccentric people, people who are very different. I think those people should be more than tolerated, they should be accepted and included. Just because their behavior is different or they think differently, as long as it's not dangerous to people. Most people who are labeled mentally aren't dangerous. They are less dangerous than the average person.

These definitions also recognize that people without the label are not necessarily "normal," and consumers agree on this. Carmen said, "I've met a lot of people who can work who are so screwed up. It's frightening. They can work, they can pay their own bills, they can go on mini vacations, they are taxpayers, so therefore they are respectable. . ." Jay said,

> So-called normal people are not necessarily mentally healthy. I passed as mentally healthy for a long time, and I wasn't, and I didn't know I was passing. Mental health—it's not an absence of pain, it's an absence of either an excess of either pain or anxiety, excess of any emotion that is beyond the normal range of experience in day to day living.

7.9 The Challenge of Internalized Oppression

When oppression is pervasive and long-term, people in a target group "internalize" the mistreatment and the misinformation about them. The target group thus believes the same misinformation that pervades the social system in which they are embedded. This dynamic is called "internalized oppression" (Sherover-Marcuse 1986). Internalized oppression can result in the non-target group reproducing the oppression they experience from the target group among themselves; for example, women fighting together against sexism may feel that other women are impeding their progress because they are "too emotional." This internalized oppression can be a barrier to effective activism. Some of the people in this study, especially those in NAPA, were aware of this dynamic. Others heard of it for the first time when I introduced the concept to them.

Kris and Ava both talked about the frustration they sometimes feel in their involvement with NAPA. Kris said,

> Internalized oppression is always a problem. This group of people have incredible patterns of hopelessness, powerlessness, victimization, anger. . . . there are some heavy energies, from what was done to people. That's an obstacle and that's something to be dealt with. Just like any oppressed group, it's easy to fight each other or argue or get bogged down in pettiness. . . . Sometimes I sit at these meetings and think, "These people, oh." And yet I'll remind myself why they are like that, and that's not who they are. Then it's easier to look at people and remember what they've been through. Then I think it's amazing that they are here, not "I wish they'd quit complaining."

Ava said,

> There seems to be a lot of apathy in the group, a feeling like, "That's too big, we can't achieve that." Or simple things like getting flyers copied where people say they'll do it and then they don't do it, or people maybe not being here. Things like that. Major struggles over motivation. Electric shock really takes away your motivation. . . . [and] dealing with the realization that humans do sick and cruel things. That really stamps out motivation in the first place, because if you get inside that, "Oh my God, the Holocaust, and electroshock, and lobotomies, and blood-letting. . . human beings do really sick and cruel and torturous things to each other, how could I really make a difference. If it's innate, is there a way that I

> can change it?" It doesn't justify oppression to say "it's innate," but I think it's where the apathy comes from.

Most of the consumers were not familiar with the concept of internalized oppression. Genett's lack of response to being called "the bi-polar on the end" during an SOS panel demonstrates how insidious internalized oppression can be. Even though many of them had not heard of the term, some consumers related incidents that showed it was present for them as a lived experience. John said,

> I don't know if this is part of the illness or what, but even before I ended up in the mental system, I always had high expectations of myself. When I was in college, I was getting letters from professional football teams. . . I've been on television, some of our games were televised, we traveled and saw other parts of the country. . . ending up in the mental health system put a big damper on all that and took away all these goals and ideas. But what they did was label them and said, "When you have these kinds of things, it's grandiose."

He went on to talk about his goals for consumer advocacy.

> When you get a taste of that kind of success, why should I settle for working in an agency in a little community? . . . I want to do something on a national level. I've got these ideas, some people think that they are really grandiose at this point, but I'm sure they thought it was grandiose to get a Master's degree in counselling, it was grandiose to think I was ever going to get a job.

While spending time with SOS, I noticed certain behaviors deemed appropriate and inappropriate by members for panels, and wondered how much this was connected to internalized oppression. Carmen often had difficulty finding people who she thought would be "healthy" enough to do a presentation. I asked Jay what would be acceptable and unacceptable behavior at an SOS event. He said,

> You don't want to present an image that's violent, because most of the time, most people with mental illnesses aren't violent. They spend more time hiding in their apartments and suffering than they do hurting anybody, or dealing with people at all. . . . You don't

want to scare the people you're talking to, you just want to inform them, besides they are cautious enough already that they don't need to hear something that's going to frighten them. They can get that from tv. . . .

As far as someone who is talking to themselves and their voices, that might actually be helpful. That might actually benefit the SOS, because you could see someone actually dealing with that problem at the time, and we could explain that really easy. . . if you're in a group of 30 people and you see something like this from an audience point of view, it's not necessarily as threatening or scary as it would be if you saw it on the street. . . . You just talk to them like they are normal and they start behaving normally.

8. TARGETS OF RESISTANCE

THE HOSPITALIZATION

I drove the five mile distance to work on a beautiful spring day in Oregon, snow still on the mountains. I went into the office, picked up the keys for the agency car, and called Joe to tell him I'd be at his apartment in 15 minutes for grocery shopping. He sounded fine on the phone, but then I got reports from co-workers that he had been acting "crazy" the past few days.

When I got to the house, I noticed the hallway lightbulb had been spray-painted red. I found Joe in the backyard burning a pile of magazines. I told him he needed to stop because the fire code prohibited burning in city limits, and one of the neighbors could call the fire or police department and jeopardize the status of the house for everyone. Joe glared at me and told me that he had to do it. He also told me, in a very angry tone of voice, to not call him Joe.

"That's not me, that's some guy who's been in the hospital. Why do you call me that?"

I glanced at his hands. The skin was peeling off and it looked as though he had burned them, or poured some chemical on them. I sighed heavily and thought, "Here we go again." I walked to the side of the yard and saw a can of gasoline.

"Joe, have you been sniffing gas?" (This is something he does when he begins to, in the words of the mental health system, "decompensate.")

"I told you not to call me that! Why do you accuse me of doing these things? Why can't I get any peace around here?"

His voice was hoarse and it was obvious that he had been yelling at other people besides me. I found out from Joe's roommates that he had been up all night, flushing things down the toilet and keeping them awake. In between telling me that he was fine and that there was nothing wrong, he told me that he had swallowed a hundred nails. At other times when he had been like this, he would end up in bars where he would provoke people into fights where he would get badly injured, and once he stood in the middle of busy downtown traffic as cars swerved around him.

As I had done so many times before, I told Joe I was concerned about his safety and gave him a sermon about taking his "meds," some variation on "You have a mental illness. It's nothing to be ashamed of. It does not make you less of a person. It's just like having diabetes, and that's why it's so important to take your medications." And this time, just like the other times, it only seemed to make him feel worse. He became more agitated, and I felt helpless as to what to do. Wasn't this the proper thing to tell him? Shouldn't it make him feel less stigmatized, better instead of worse? That's what I had been trained, anyway. I was baffled.

Something clearly needed to be done, but our choices were limited. Joe told me all he needed was a good cup of coffee and some companionship. This was not an option because, in the state he was in, any coffeehouse would have kicked us out in no time. He told me all he needed was a few more dollars in his pocket, that it was impossible to make a living on the $2.00 an hour he earned from his janitorial training job and less than $400 a month from social security. I didn't think the answer was that simple, yet I couldn't help but wonder how those very real facts were affecting his mental health, as they would anybody.

Since my presence and questioning seemed to escalate the situation, I decided to go back to the office and talk to my co-workers about a plan of action. We came to the conclusion that Joe would need to be hospitalized, for his safety and for the sake of his housemates. There was a deep pit in my stomach. There was a giant chasm between us that I did not know how to bridge. We were talking two different languages, living in two different worlds. Joe's world at that moment was full of fear, anger, pain, and demons. Unfortunately, it was also the same world that at other times was full of star gods and goddesses and fishing stories. How could I suppress the one and keep him safe without taking away the other? How could I avoid putting him through the process of being picked up by the police, handcuffed, taken to the psychiatric hospital (in the same building as the county jail), and being injected with shots of Haldol? I could find no answers. The next day, the police located him and committed him to the hospital.

Survivors and consumers target their resistance at people in a position of power and authority who attempt to define their experience. These include: parents who speak "for" them; psychiatrists, psychologists, and other mental health professionals; stigmatizing news items and film portrayals; and government and insurance criteria for receiving or being denied treatment and benefits. These people are part of larger social institutions: advocacy groups composed primarily of non-survivors and non-consumers, the media, economic and legal systems, the medical model, and ultimately, the culture itself.

In this section, I explore the differences and similarities in survivors' and consumers' critiques of these institutions.

8.1 Advocacy Groups

While there are differences in world view and strategies between the consumer and the survivor movement, SOS members' identity as consumers working for improvement *within* the system does not preclude them from observing that advocacy groups comprised mostly of parents, family members, and professionals rather than survivors and consumers can be disempowering. One of the largest of such groups is the National Alliance for the Mentally Ill (NAMI).

NAMI started in 1979 with two mothers in Wisconsin and now claims over 140,000 members in all 50 states, most of whom are parents of people with mental illness (Foderaro 1995). The group provides support and information for families and lobbies for legislation which will maintain and increase funding for research on the causes and treatment of mental illness. On both counts, they have achieved some measure of success.

Both NAMI family members and psychiatrists emphasize a biological approach. For families, it is a way to escape the shame and blame for a long time pointed at them by some of the psychoanalytic and other literature on mental illness. In many cases, they are extremely sensitive to any suggestion that environmental factors might have played a part in the course of their childrens' illness. This emphasis on no-fault seems to lead many parents to a strong endorsement of medication as the best and often the only way to treat mental illness.

It was my observation that consumers may have had a deeply ingrained fear of biting the hand that feeds them, but they certainly nipped at it with tenacity.

This criticism was usually more covert than overt. During lunch before one SOS presentation, members 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 parent 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. Sharon suggested that NAMI should be renamed "Parents in Denial." Both Carmen and Sharon said that NAMI does not include very many consumer voices and does not seem to want to.

SOS also insists on complete autonomy from NAMI influence on their organization. When SOS was starting up, 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.

Consumers see one of the main problems with parent groups as a lack of recognition or responsibility that they could have had some influence on their child's mental health. Carmen said,

> I'm sure of these parents, of the ones I know, none of them would have done it deliberately, harm the children emotionally or psychologically. But it happened, maybe there was a predisposition, maybe there was a child stuck in the middle that didn't know how to get their own identity. . . . But I think in their emphasizing so much that they are not at fault, it really makes them more guilty.

Another woman who was a survivor of childhood sexual abuse wrote an article which appeared in *The Rights Tenet* (a newsletter from the National Association for Rights Protection and Advocacy). She wrote:

> We are not out to blame parents but to request accountability. What's been done has been done. We now have the responsibility of advocating for care. Just as I would argue that most psychiatrically labeled do not commit violence, I would not deny that some do. Likewise, the majority of parents of the psychatrically

> labeled are loving and caring. But some few parents have committed child abuse (Blaska 1994:6).

Survivors note that another reason that non-survivor or non-consumer advocacy groups endorse only the medical model of treatment is embedded deeper in our assumptions about health and illness. Our society's reification of psychiatry and the helping professions can lead people to feel inadequate to deal with someone going through an emotional or mental crisis. The family and the community become unable or unwilling to take on involvement and responsibility. Leonard talked about what he saw as the notion underlying much of psychiatric practice:

> ". . . if we don't take care of these people and give them this treatment even against their will, the likely outcome is going to be either suicide or chronic mental illness." When psychiatrists who have tremendous power and influence say that to parents who are really desperate about their children and they don't know which way to turn, and the parents have been conditioned to think of the psychiatrists as helpers and as experts on this issue, and they are told something like that by a person in authority, it makes them very very scared. At that point, they are more apt than not to turn the whole thing over to the psychiatrists. "Let the experts take care of it, this is beyond our ability." I don't agree with that at all. It's not beyond anyone's ability. This is a way of abdicating one's responsibility. . .

8.2 Media

Consumers place major emphasis on targeting stigmatizing and stereotyping portrayals of mental illness in the media. SOS members frequently cited the media as a main source of misinformation about mental illness. John talked about a car commercial he had recently seen with a friend:

> . . . they say, "Don't have a nervous breakdown." [My friend] and I were watching it the other day and we looked at each other and said, "I don't like that." . . . It's like when you hear about schizophrenia, people are always misusing and saying it's a split personality. I see that a lot in the newspaper or magazine and it's misleading and it gives people wrong information which contributes to a whole lot of people in society not really understanding what's going on with people with mental illness.

John also commented on the way those portrayals work to separate people.

> What also puts me off is when you see it on the news or in the newspaper. It just seems like a way to distance people. . . when you know somebody who struggles with that everyday, then it's different if you don't know anybody. . . . If you know people with mental illness, it's not funny. We can joke amongst ourselves, but I don't think it's cool, I wouldn't get up in public at an SOS and make fun of mentally retarded people or even mentally ill people, because it's dear to me. . . .

Another critique of the media is that it reinforces the public's view of the mentally ill as dangerous, psychopathic killers. One of the ways consumers and their allies have combated these images is through an organization called the National Stigma Clearinghouse (NSC), based in New York City. NSC publishes monthly reports which target negative media portrayals of mental illness along with information on how to voice opinions and take action with the responsible media source. For example, a December 8, 1995 "Stigmabusters Alert" notified people about an advertisement campaign from RC Cola with the slogan: "WARNING: KICK [name of the product]: The new hardcore, psycho, nitro drink." NSC found the use of the word "psycho" and the suggestion of violence to be offensive. The alert suggested writing letters to billboard companies, supermarkets, and grocers, and networking with other groups that would be interested in preventing the marketing of violence to children.

I find this is a commendable effort, but limited by the fact that these portrayals are invariably countered with only one other interpretation: that mental illness is a biological illness that can be treated like any other. One of the stated goals of NSC is to "promote accurate use of medical terms associated with psychiatric disabilities." The critique continues to sit firmly within the biomedical model, and the danger is that it can lead towards complicity rather than group activism and social change. Dr. Paul Fink, a past president of the American Psychiatric Association, went on record to encourage people with a history of psychiatric disability to lie about their past when they seek work because, "the stigma is there, and to deny it and sacrifice yourself by telling the truth makes no sense" (Rogers 1995:8). It also fails to address the sources of stigma and discrimination that come directly from the mental health system, the effects of psychiatric labels and diagnoses, and what many survivors and consumers feel is the worst embodiment of stigma—the law which permits forced treatment of psychiatric patients, a doctrine found nowhere else in the practice of medicine (Reidy 1993).

In contrast, survivors sometimes take steps to actually re-claim derogatory words as empowering, echoing a similar strategy among gays and lesbians who have embraced the term “queer.” David said survivors sometimes call themselves part of the “Crazy Folks Movement.” Kris said, “People can take on that they are crazy and mad in an outrageous way, like, ‘Yes, I don't conform. I don't work 40 hours a week and I'm not a robot in the financial district. I question conformity.’” She saw it as a strategy to access more power and control, over both their own lives and within political and institutional systems.

Survivors also noted ways the media and the medical model collude to restrict the kind of information available to consumers and survivors. Leonard said:

> *The New York Times* had a story several years ago on schizophrenia. It was a four-part series, with each article beginning on the first page. Not one mention of an alternative way of looking at schizophrenia. Thomas Szasz, perhaps the strongest critic of the schizophrenic model, was not even alluded to. . . . When the psychiatrist says these things about mental illness, for example, that it’s a brain disorder, no one says, “Let’s see your evidence.” It’s presented not as a proposition or a hypothesis, it’s presented as fact. And there are damn few people who would dare to challenge it.

Leonard noted that the ultimate way of disempowering the movement was to not give it any publicity.

> The way that they [the medical establishment and the media] deal with me and other critics is just to ignore us. Because once you are contested in your views, right away it becomes a controversy. But in their minds, there is not controversy. They just continue doing what they are doing, they publish their articles in favor of drug treatment, shock, and the medical model of mental illness, without hardly any criticism. Why should they pay attention to us? No one else is.

8.3 Economic and Legal Systems

Consumers spoke out about systems which are set up with more disincentives than incentives. John talked about the process of getting benefits:

> . . . when I got on social security. . . that really took away a lot of the incentive. . . Just to go through the process of having a breakdown and getting sick, psychologically sick, that takes away a lot of your spirit. Then getting a check takes away a lot of your spirit. For a while, even though I was going to the psychiatric hospitals, I was still working. I still wanted to work. When they told me that they wanted to put me on social security, I was like screaming, "I don't want to get on social security, that's for sick people." . . . the message I got when I was in the hospital, which was the mental institution, if I wanted to get out I had to get on social security.
>
> I remember listening to somebody on the radio say that only one percent of the people who end up on social security ever get off and go back to work. I think what happens is a lot of people, after you haven't been working for a long time, you just can't jump right into a well-paid job. In between there is a lot of other kind of work you could do, but it's not to your benefit to do because it's not going to pay the bills, probably not going to have any health benefits. . . . health insurance is so important, people with disabilities know that they need that. A lot of people who are really healthy don't think about it, but after you've had a disability you know how important it is to get your medication and see your doctor. You need those health benefits."

During Ann's stay in a psychiatric hospital, she received a letter from her insurance company notifying her that they were terminating her psychiatric benefits because they said they didn't have to provide long-term care in a case like hers, considered a permanent situation. She was outraged. "If you have cancer, they don't say 'Well let's see, you haven't died yet, but you've used up your sick month.' I don't understand it." Her doctor recommended that she stay another couple of weeks and then go into a day program, but the cost was so high that she was unable to do so. She ended up with a $48,000 hospital bill for the time she was there. After this incident, no other insurance company would give her coverage.

Carmen said, “Most of us live in poverty, and we’re all uninsurable, so that limits our opportunities to provide for ourselves medically. The system makes it very hard to get out of the system.” Scheff (1966) and Estroff (1985) both also noted this paradox: in order to survive economically, ex-patients must continue to display symptoms to remain eligible for social security, treatment, and other assistance.

The legal system which sets the criteria for commiting people to treatment was also a target of resistance. Commitment procedures usually revolve around the phrase, “a danger to self and/or others.” Leonard’s reflections on his experience show how this criteria can be culturally-influenced:

> . . . in my records I think it does say I was a danger to myself. The very fact that I was a vegetarian was to them an indication of my dangerousness. How could you eat without meat? George Bernard Shaw was told by his doctors that if he didn’t eat meat he was going to die as a young man but he lived to be 94. . . .

Almost everyone, survivors and consumers alike, had an incident to relate about the humiliation of being brought to a hospital on a “Fifty-One-Fifty” (written: 5150), a legal procedure in the state of California by which a person can be involuntarily detained for 72 hours for a psychiatric evaluation if they are considered to be a danger to themselves or to others. Frequently, people who had to go into a hospital on a 5150 were picked up by the police at their homes and then transported in handcuffs with a crowd of neighbors watching, even if they showed no resistance. Carmen said when this happens, “You’re afraid to go back home because you’ve been deemed a nut case.”

8.4 The Medical Model

Survivors and consumers both had plenty to say about the mental health system and the medical model, but with a difference. Consumers spoke about individual professionals by whom they felt mistreated, but rarely engaged in critique of the whole system. As John said, “Even though I’ve got a lot of complaints about the mental health system, I think it’s good it’s there because a lot of people would have nowhere to turn, nobody to give them the help they have.”

Survivors, on the other hand, were vehement and comprehensive in their critique. Leonard said, "I think there are more people who commit suicide as a result of their experiences with psychiatry than those who committed suicide because they lacked psychiatric treatment and intervention."

Survivors were critical of treatments they had experienced as damaging, specifically, psychiatric drugs and electroshock (ECT). David and Leonard commented that the effectiveness of these treatments is based on the short-term view of wellness held by the medical model. About drugs, Leonard, said:

> . . . they do work in a sense. They may provide some relief, if you get the right dosage and the right amount. For a time it can appear to work because they reduce the anxiety by making you apathetic. If you have had a lot of energy and were not able to control that energy or were doing stupid things that bothered other people and bothered yourself maybe, when you're taking the drug you have less energy to do them. So in that sense, it does work. But what the psychiatrists and many victims of drugging don't seem to appreciate or won't talk about is the long-term effects of these drugs. They're very powerful and harmful. Probably most people who take drugs like phenothiazines, e.g. Haldol, and Thorazine, for extended periods of time will end up with tardive dyskinesia or other very serious neurological problems including dementia. . . .
>
> The latest fad drug is Prozac, an antidepressant. It's supposed to be used for serious "depression," what psychiatrists call "clinical depression." But it's become so popular that it's now being prescribed to people who are mildly unhappy or a little bit out of sorts with themselves, or when their morale is shot. Some doctors are passing it out like candy. Prozac is very similar, as I understand it, in its chemical structure, to amphetamines. It's an amphetamine-type drug that will give you a buzz, a little high, more energy, and make you think that you really are feeling better. Of course, it takes you out of yourself and you begin to function better, at least in the short run. While you are on this drug, you don't have to think about your problems. You can just go out there and relate to the world less reflectively and less stressfully.

David said that a few psychiatrists who had tried neuroleptics to see what effect they had actually had to quit their work and couldn't even use a phone. But they wrote in the literature that they found the drugs a successful therapeutic modality precisely because they had such a powerful impact on numbing emotion and physical energy.

While the majority of the SOS members used medications and found them helpful in dealing with symptoms of their illness, they also commented that the side effects were very unpleasant, and a significant tradeoff. A few of them found medications not helpful and instead used therapy. None of the NAPA members took medications and all felt that they did more harm then good. But, as Kris said,

> I think one thing that's real important, and in NAPA we talk about this, is to not judge people's decisions. People have a right to identify themselves with their own label, whatever that is, and to treat, heal, do whatever, take whatever paths toward their healing they choose to do. If that's medication, then that needs to be okay and not judged. I think that's really important. . . . It's really about freedom and choice and I don't think anybody would be against that.

Of the five survivors I interviewed, three had personal experience with ECT. Of the consumers, only Carmen had been shocked, and she agreed it was horrible. Leonard was especially passionate in his condemnation of the procedure, based on his own experiences, and explained his understanding of how ECT works and why psychiatrists can justify using it:

> It's really ironic that ECT can on the one hand produce a measure of euphoria, you feel high, and then after that is apathy, the depression intensifies. Euphoria is an interesting indication of brain damage. One of the indications of an insult to the brain and resulting brain damage is that the person will feel high for a while. . . . That is the energy that is giving you almost an adrenaline rush to enable you to want to continue on, and the energy to continue on during a very critical moment in your life. If you've been hit on the head, for example, that could be very dangerous. You're vulnerable. But that additional energy gives you the juice to continue. . . . The same thing happens with electroshock. Only here the trauma is purposefully induced.
>
> Sometimes people will report feeling good after shock treatment. The doctors think that the patient is in remission, getting better, let's continue on with the treatment. Really, they are talking about

> one of the effects of brain injury, which would be clear to any neurologist, but psychiatrists don't see it that way. That's why very often it will be recorded in the notes that the person reports feeling better. So the psychiatrist is really thinking short term. That's the way they think: "They're feeling better, well let's do more of it, it must be working." But what they are reporting are the effects of brain damage, not that the treatment itself is working in any real sense of the term. The problem is that the euphoria, when it occurs, is of short duration and the brain damage that causes it is permanent.

While those aligned with NAPA and the survivor movement tend to be very critical of any sort of medicalization of madness, some SOS members were actually able to find openings in it. Genett said that medication helped her better organize her thoughts so that she could actually get to a point of becoming involved in activism. And, because a psychiatric diagnosis is linked with a system of government benefits, economic and work openings were created for some of the people who chose to identify with that label. Genett told how she was able to finally get a job that she loved, ironically, through being fired for having a manic episode at another job she hated. She said her employer at the first job told her,

> "We can't deal with this [the manic episode]." They were reading up on the ADA policies and they gave me a few choices, I decided to take the severance package. . . . Since getting out of that situation, I felt that everything was lifted off my shoulders. . . . Now I'm doing work that I always wanted to do, working at CUAV [Community United Against Violence] as a volunteer. That's an organization that fights against hate crimes against gays, lesbians, bisexuals, and transgenders and also handles domestic violence cases within the gay, lesbian, bisexual, and transgender community. Being liberated gave me the chance to come out of the closet as bisexual too.

Jay said,

> There are a lot more services for the mentally ill than for the homeless, and I would have been strictly homeless. By getting into the mental health system, I have an organization that helps me in crisis situations. . . Housing - I would never probably have found

> one of those roommate services. I was too shy to go out and do anything in my life, and too worried all the time, and I probably would have just drifted out, and all of the sudden, "I have no more money, where do I go? What do I do?" The system has a lot more services for someone who is mentally ill than someone who just doesn't have any money. That, as an advantage, has been quite a help in the past four years.

One clear consequence of the medical model is that madness receives a label, a "diagnosis." Both survivors and consumers commented on the effects of being labeled. While the generalization can be made that consumers are more embedded in the system and seek to reform it rather than abolish it, they were loud and clear in stating that labeling is disempowering. Several SOS members said that the most stigma they had experienced had come not from the general public but from the mental health system. As Thomas Scheff (1966:14) pointed out, the medical model and the psychoanalytic approach are an example of what is called a "negative feedback loop" in general systems theory, that is, a self-maintaining system which takes any deviations from that system's steady state and explains them in the context of its own beliefs. Thus, there is little room for subjective truths. This is illustrated by Jay's comment:

> The most significant feeling of being excluded comes from the system itself. That's not saying anything personal against the doctors or counselors or administrators, it's just they deal with the label. And once you're labeled, if you get angry, it's part of your mental illness. If they get angry, they're just upset. That's the major difference. . . . Lately I've started to realize that I don't want the label for myself, because that limits what other people think I can do, especially people in the system. I think a lot of them hear the label and they instantly think, well, get him as a job as a janitor. That bothers me a lot because I can do a lot better than that. . . .

John also said,

> The people that are the most stigmatizing, people who seem to be the ones who want to remind you, are professional people. I'm really uncomfortable with that, because we had a counselor here who has since died of a drug overdose himself, and he was always referring to "our disabilities." . . . It was to reassure himself, it was like pushing us away, and saying "I'm okay and you're not."

From a survivor perspective, Kris noted,

> [Psychiatry and psychology] takes individual differences, personality traits, tendencies, and they are a problem, rather than they just are. If I'm seriously stressed out, I don't sleep very much. I have a lot of physical energy. Well that's the time to really swim a lot, or do yoga. It's an opportunity to do what sustains, or get a lot done. It doesn't need to be pathological.

The effects of labeling are so pervasive, long-term, and damaging that even people who have already “come out” are still wary of discussing their label. When I interviewed Ava and asked what her diagnosis had been, she said, “They gave me a bunch, depending on the doctor.” Then she looked at me and said, “God, now I’m getting paranoia, thinking about like, ‘Is she really who she says she is [referring to me]? What do you want? You’re from Alta Bates [a local psychiatric hospital], I know it!’ I have that stuff come up a lot.”

David said,

> . . . the labeling process itself is a disability. The Americans With Disabilities Act says that too. If society mistreats you because of your label, then that is a disability, and therefore you can qualify under the ADA. . . . That’s what I see as the source of stigma, the actual labeling. Stigma means brand, and you look at who’s doing the branding [laughs]. You don’t say “This brand doesn’t mean anything.” You know? “Well then stop branding me, you know!”

Even the movement itself gets labeled as David points out.

> They always try to peg us as being anti-drug or anti-psychiatry. Our common denominator is simply about being pro-empowerment and pro-choice in the rights movement, so it’s really unfair of them to use language about us that we don’t ourselves use. They’re still labeling us.

8.5 Culture—An Anthropology of Normality

At one point during our interview in a coffeeshop, one of David’s friends waved and asked what we were doing. David explained that I was working on my thesis and said, with a twinkle in his eye, “She’s studying normals. We’ve been examining the problems in that area.” David coined the term “anthropology of normality,” which I adopted to make sense of the things people were telling me about ways in which they had developed an acute awareness of the behaviors and emotions needed in order to navigate through the “normal” world.

People who are labeled mentally ill or “crazy” in our culture are astute observers of what constitutes “normality.” They have to be, because they need to know strategies to pass as “normal” in order to survive in a world that discriminates against mental illness. Jay said,

> When you have high anxiety and you’ve been extremely shy from the age of three and you study everybody’s body language every second of the day, just to avoid being embarrassed by something, you get really good at telling what people are going to do. I’m not perfect at it, but I’m good enough for what I need to do. Tone of voice, inflection, expression on the face, body movement, you can pretty much tell how they are going to react in general.

In a way, survivors and consumers are like cultural anthropologists. Again, a description from Jay:

> It’s like being dropped into an entirely different culture somewhere else in the world, knowing nothing about it except what you’ve seen on television, and trying to fit in right away. . . And you have to try to figure out all the subtleties of socialization and culture all by yourself.

In this sense, both survivors and consumers critique culture. But while both are acutely aware of definitions of normality, consumers usually stop at the point of looking at how they don’t fit in. Survivors go on to question why society doesn’t allow them to fit in, and look at the issue politically. David talked about this “not fitting in” in the language of oppression:

> Oppression is like oxygen, it’s everywhere but people don’t notice it, or another example is that it’s kind of like when you’re looking at those parking garage things and you’re about to drive in and those things stick up like this [David shows me with his hand]. As you’re driving in you’ll notice it because they’re going to puncture

> your tire, right? So you stop and you pay to get in. But when you're leaving, you just blow it off, you just blow right through it. It's the same thing if you're privileged, often you won't see the oppression, and it really can create a lot of mental problems for the people that are being oppressed, because they can see it.

Critiques of how our culture views and treats madness come strongly from the survivor movement. Leonard's comments touched on the interconnection between the medical model, the scientific paradigm, and our cultural assumptions:

> You cannot talk to a psychiatrist about these issues without them blowing up and getting extremely angry, just like if you were to confront a Nazi who was in the SS about his activities during the war, murdering people, they couldn't address that. . . . They believed in what they were doing as much as what the psychiatrists believe in what they're doing, and they were indoctrinated that way. The whole culture, the whole society in Germany, was inclined, to begin, with to hate Jews, just like in our society, before any young man or woman goes to a medical school they are inclined to feel this way about mental patients. They think there is something wrong with them and society has to really take them in hand and deal with them and control them because they are dangerous. They are regarded as a menace to society, just as the Jews were. The Jews were a cancer in the Aryan body as far as the Nazis were concerned. They had to be gotten rid of or the whole body would be destroyed. If you accept their premise, the Nazi extermination program was perfectly logical. If you accept the premise of modern day psychiatry about how mentally ill people are about to murder themselves or other people, you've got to intervene to protect them from themselves and to protect society from them. You're doing them a favor. And they've worked up this belief system whereby the mental patient, if the treatment works in their terms, will actually thank you for it. Someone is lobotomized. "Thank you for cutting up my brain, Doctor. Appreciate it a whole lot." And then to smile in his face. Because often times that's the only way you can get out of these institutions once you've been locked up. . . .
>
> [This is] a system that pays the salaries of about five hundred thousand people. They are all cooperating in this kind of brutality by at least keeping their mouths shut. A lot of them are actively

> cooperating by being participants with the ECT doctors. Either setting people up for electroshock, talking them into it, or actually helping the psychiatrist as the individual is being assaulted with electricity. Furthermore, you have all the families who are involved in this. Most of the people given electroshock have someone on the outside who has signed a consent form, so they are also accomplices in this. Then what about the whole medical profession? We're talking about seven hundred thousand medical doctors. Their association, the AMA, has endorsed electroshock. We're talking about the whole scientific community, because what is the medical profession? It's the human relation arm of the science industry today. And what is the science industry? It dominates the way we look at the world. How wonderful technology is, all the advances we've made, we live in a modern age, aren't we wonderful, we all believe in the scientific creed. We're talking about the entire culture. Everyone is involved in this.

Kris also talked about the pervasive influence of science:

> Science is considered legitimate in this society, very valuable, very honored. If something is scientific, it means it's real. If something is not scientific, it's not real. It's invalid, hocus pocus. Women, intuitiveness, all of that is outside the mainstream. It's high up in the hierarchy, so when they say things are physical and scientifically proved, then that validates that there really is mental illness and it's biological, supposedly. I reject that. I don't think that's true. But again, it's associated with those who know, those who make a lot of money, those who are professional, those who are legitimate within the society. The rest are just mental patients, or crazy, or emotional. We worship the mind and rational, linear thinking. Emotional is invalid. All this stuff is about having a lot of emotion.

David pointed out that many patterns of what is called "normal" are destructive and at the root of the current social and environmental crises. He sees the survivor movement as an integral piece in a larger movement toward social transformation.

> . . . 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 [the mentally

> ill] serve is that there is a need for a scapegoat. [They can say} "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.

What do these patterns of normality consist of? Both survivors and consumers give us clues, as they relate their strategies for trying to "fit in." The responses I gathered clustered under several categories, which I present as a beginning contribution to an "anthropology of normality."

8.5.1 Suppression of Emotions

Almost everyone noted that our society is one in which we are not allowed to express a full range of emotions, and that this is a lesson learned early in life. Ava commented that ". . . we teach children from a very young age to 'quit crying, don't be sad.' We need to teach children that it's okay to feel what they feel and teach them how to sit with their own emotions and sit through those feelings, as opposed to smother them."

Jay talked about what normal meant where he grew up.

> In Iowa, they aren't very exhibitionist in how they care about each other. The normal culture in Iowa is you withdraw from emotions, more or less. Most people showed a lot more emotion than I did, of course, but there's not a lot of hugging and kissing and carrying on all the time. You don't necessarily talk about how you feel with each other a lot. . . . I sort of intensified that a lot, about a hundred times! And that caused a lot of my stress. But it is the culture there–deal with your own problems, grow up, handle it yourself, that sort of thing.

Kris thought that a healthy society would be one in which people could have a wide range of emotions.

> I think a healthy person would be expressing many more emotions than is generally acceptable in this society. Certain cultures have that more than others. This one doesn't have a whole lot of it.

> Certain parts of the world, it's more acceptable for people to scream and yell and grieve. . . . When I think about all that's happening around us that we are supposed to deny, it's a wonder that we're not screaming right now!

She felt that what is called "mental illness" would decrease

> . . . if we were comfortable with people having a lot of feelings and it wasn't a big deal. I think that people get freaked out and crazy, or mentally ill, from that isolation. I think something can start out as a simple crisis and escalate because of other people's reactions.

8.5.2 Suppression of Spirituality

For Carmen, "covering up" meant maintaining an appearance of "intellectualism . . . being as smart as everybody else. . . getting away from the personal stuff." This "personal stuff" often takes the form of an interest in spirituality, and a desire to share these experiences with others. However, this is often suppressed because of a fear of standing out as "not normal." Leonard gave an example of being at a cocktail party:

> . . . you could bring up religion or God once, but if you do it a second time, it's likely that you won't be invited back to another party. . . In our society there is a lot of emphasis given to sexual repression. That's very clear, and I think it's really a good thing that subject is being talked about, but still, spiritual repression is as widespread as it ever was. Spiritual repression is when you can't talk about spiritual matters, or you can only talk about them on a very superficial level and then people will want to move on to something else. If you persist on that subject, then you are thought to have an obsession with religious ideas.
>
> . . . Half the society believes in the visions of the Bible, but anyone who claims to have a vision would right away be tagged as a schizophrenic, because we know from psychiatry that having delusions and hallucinations are two of the prime psychological manifestations of schizophrenia. So they've got you nailed. This is one of the ways that society has of suppressing spirituality, by labeling people who talk about spiritual things in a serious way, regardless of whether they are on target or not. Just to talk about these things, regardless of what you say about them, is right away

> to put yourself into a psychiatric cubbyhole—it's a prime indication of pathology.

Ava related her experience with other realities:

> Throughout my lifetime I've seen a lot of spirits, felt a lot of spirits, and have had a lot of experience with things they would call psychotic. That was one of the things I read in my case notes. One of the ways they were labeling me crazy was I have this thing that there are three realities, and they are all real: your waking reality, your dreaming reality, and your after-death reality. Those are three parallel realities existing at the same time. I had this whole belief system and that was totally "psychotic." That was when they put me on psycho drugs.

8.5.3 Pushing the Limit

Another expectation of American culture is that people should function well in all areas of their life despite signs that their body or emotions are exhausted. This is perhaps closely related to suppression of emotions. Carmen talked about her vulnerability to fatigue, and how stress worsened her symptoms so she needs to really slow down when feeling stressed or tired. But her experience of "tired" is not perceived the same way as someone else. She related an incident where she wanted to leave a social setting and told people she was tired.

> . . . I was exhausted. I just wanted to get into my robe, I wanted to read or get in someone else's reality. I wanted to say goodbye to them at four o'clock and they weren't ready to say goodbye at four o'clock, so I had to string myself out until 10 to say goodnight and goodbye to them. . . . I was trying to tell them, but people weren't hearing me. I'm telling them I'm very tired, but they think tired to them is degrees of being fatigued, and when I say I'm tired, it means I can't move. But when they hear that, they think it's probably just a little fatigue.

In the same theme, Kris noted deep grieving is not permitted in our society, and little recovery time from it is allowed. She imagined a healthy society as one in which "it would be okay to grieve for a long period of time when bad things happen. Now you're supposed to grieve briefly and get back to work."

8.5.4 Diluting or Hiding Differences

People noted that there were strong cultural expectations around ways of dressing, speaking, eating, and other activities that were all occasions for trying to "fit in." Deviating too far from these expectations could draw attention and suspicion to them. Carmen said she had gotten very good at "covering up" her illness and explained, "I always tries to look good. If I don't look good, I'll stay in the house."

Genett had an accent that was part Texan and part Tagalog (a Filipino language), and because she was trying to emulate the "perfect English" she thought other people spoke, her speech pattern was markedly different than her friends. She remembered how self-conscious she was about it when she was growing up:

> If I opened my mouth, if I were to answer someone, I would sound really goofy. I have a lilt when I talk, and back then it was considered, in the schools I was in, to be one of two things. They would say, "You're trying to be white." Or, "You sound goofy or stupid."

I asked Jay what it would mean for him to "fit" in the world. He said,

> It would be really strange. I'd have to readjust my entire identity. . . . Say you and I met at a restaurant, and I wanted to go out with you. I wouldn't have the slightest idea how to be witty enough or charming enough to talk you into that. . . . If you don't meet someone or know someone to introduce you to certain situations and explain if you're doing something wrong, you either have to be really sharp and figure it out yourself, or you make a lot of mistakes. . . which is really painful. Or you just pick it up as you go along. You stay away from everything, like restaurants. You've noticed—I go into a restaurant and what do I order—a hamburger. I order something I'm familiar with. I had an eating disorder until I was in high school; I couldn't swallow meat. I put meat in my mouth and I would start to choke, so I don't even know the names of some of the foods I'm supposed to be ordering.

9. VICTORIES AND VISIONS:
THE OUTCOMES OF RESISTANCE

What have been the results of the organized activism of survivors and consumers? As David Oaks says, ". . .in such a difficult struggle, you have to really look to try to find out where are the victories." David cited an article (Everett 1994) which identified two areas of major change over the past 25 years: first, an increase in the representation of psychiatric survivors and consumers on decision making boards, and second, a change in the language in the mental health system which now words like "empowerment," and "consumer-driven," and "mental health consumer. David said, "For me, obviously, I don't focus on those at all, we're working on something else, but in the big picture, I think that those are legitimate victories. And thousands of people are involved in them, and so I think we need to appreciate those." David's quote reveals both the shared vision of consumers and survivors and the differences between the two groups.

9.1 Political Victories

The social activism catalyzed by psychiatric survivors and consumers together with the Disability Movement has resulted in at least one major strategic victory: the passage of the Americans With Disabilities Act (ADA). The ADA is instrumental in putting into place a mechanism for people with disabilities to fight discrimination in the workplace and other venues, and also redefines disability itself. According to the ADA, a person has a disability if he/she:

- has a physical or mental impairment that substantially limits one or more of his or her major life activities,
- has a record of such impairment,
- is regarded as having such an impairment

This last point is important to people with psychiatric disabilities because it re-situates the definition to include social and cultural attitudes. It is the first legislative attempt to address the disabling effects of the label itself.

Consumer groups working largely within the existing system of mental health and psychiatric care have garnered recognition as agents of change. Dr.

Herbert Pardes, former director of the National Institute of Mental Health and dean of the School of Medicine at Columbia University, said, “The consumer and family movement has been one of the most important developments in centuries in the care of people with psychiatric illness. They’ve become a very important force in mental health policy” (Foderaro 1995:1). The clout of these groups has been used to fight proposed budget cuts in mental health care, to highlight issues of discrimination in health care, to include the mentally ill in the Americans with Disabilities Act, and to address stigma and stereotypes found in the media.

But the influence of the more radical survivors who preceded these groups should not be overlooked. It was they who, in the words of Sally Zinman (1996), “pushed the mental health system to frontiers it hadn’t been before.” It is unlikely that there would be mandates for equal representation on decision-making boards if it had not been for their persistent and intrusive actions in the early days of the movement.

Other victories according to Sally Zinman (1996):

- there are over 3,000 self-help initiatives across the country
- there are professional advocates and advocacy groups across the country
- tightened commitment laws in every state, making it more difficult (but still not impossible) to forcibly commit someone to treatment
- in California, county-funded patient rights organizations
- many concepts originally created by the survivor and self-help movement are now incorporated into mental health systems and have been backed up by rehabilitation research, including supported housing and employment and peer counseling

Sally says, “Our voice is now being heard, although I’m not always sure it’s being listened to.”

Ava saw victories on a more individual level,

> I feel like one person coming up [at a presence against ECT] and saying, “God, I didn’t know, and I’ll tell all my friends,” is a big victory. Even since doing NAPA, I think doing the presence the last time was a really big victory and having those two young men seeing that their niece was locked up in Alta Bates and going up and saying, “Listen.” And really feeling like they heard me, was a huge victory.

Ava's story also received much wider coverage when she was asked to do an interview for the television show "Hard Copy."Ava reported that the day after the show aired, David Oaks got four phone calls from people who were about to get ECT or had a relative about to get it who had changed their minds. NAPA members also succeeded in meeting with California congressman Ron Dellum's office to push the government to take a closer look at the consent forms used for ECT.

9.2 Resistance as a Healing Process

On a more personal level, both consumers and survivors spoke about the healing that they 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, another SOS member, 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.

Carmen said that for her, the benefit of speaking out has been, "Self-esteem. . . . Most people think we're really courageous, and that gives you a lot of self-esteem. . . . It makes me feel good. I think that the professionals who are going out there to serve the mentally ill are one step ahead because of hearing us."

Genett said that she finds speaking, "Liberating! That's how I feel. Just doing this [the interview] is liberating, because I love speaking now. This is so addictive! Before, I was the last person on earth that you would expect to go up in front of everybody and speak."

Ava said,

> That's been the most empowering thing, connecting with other people and identifying it as a society problem and not as an individual problem, and trying to help other people get through it, and trying to work to ban it. . . . just knowing that I can make a difference. That's the whole thing about my life, I felt like, "I don't matter because of what I've been told, and that what I have to say doesn't matter, and I've never been taken seriously. Being the identified patient, you are not taken seriously. So doing the NAPA work and getting the validation. The first meeting I went to, Ted and Leonard both came up to me and said, "You only had it two and half years ago? You're amazing! You've healed so fast, that's incredible, you must be really strong." So the validation of yeah, they fucked with me, but they didn't kill me. . . There's been a lot of strength that's come from doing the NAPA.

9.3 Visions for the Future

I concluded all the interviews with the question, "What is your vision for a world where people with psychiatric disabilities, or whatever you choose to call the experience, are treated fairly?" I encouraged people to be as "grandiose" as they wanted to be.

For Genett, mental illness would become

> . . . an everyday thing, it's something treatable, and we can take care of it, just like other diseases. Go to your doctor, or whoever you see, alternative doctors. Just get it treated and you'll feel better about it. I do!

Carmen wanted to see attitudes and a system of care like that in Europe:

> Families don't seem to have as much stigma in Europe. They embrace their family members in a matter of fact way. In so doing, I think they give the mentally ill person a better start in getting well. . . I'd like to see it treated just like as if I were born with cystic fibrosis, or with mental retardation. . . To accept it and embrace it

> in the family and treat it as "normal" abnormality. I don't see that happening in this country.

Kris also had a vision of community-oriented care.

> I'd like to see much more community, intergenerational systems where people are coming together. Now, the family has broken down. Old people go to nursing homes, lots of single parents, children spending a lot of time either in school or with paid day care people, but nothing has replaced that. I'd really like to see a lot more different kinds of communities and families, not necessarily based on blood relationships, but commitment.

People had visions of alternate treatment centers. Kris envisioned a place where, "people could go if they were in crisis where there wouldn't be a lot of intervention. People would have support, but could do a lot things, similar to holistic retreats. . . . People could get massage, do art, movement, safe places where people could really emote. They would have other people around."

Leonard said,

> For the people who now get caught up in the psychiatric system, clearly what is needed is a place of retirement or refuge from the world, on a temporary basis, for as long as the person wants to be away from the world in order to make these changes. Some people can go through these changes in a supported environment very quickly. Some people really have to start from scratch and learn everything on their own. I think that the whole process of transformation can take place in very quick order if the needed information were available to people. Oftentimes, they need a place where they are going to be allowed to be themselves, to become themselves. Ideally, this "place" would be the family home. There would be alternative places as well. . . .
>
> . . . There can be no time limit affixed to this. It has to be strictly on the basis of what the individual feels is right for them. . . You'll only get good results where there is freedom. Freedom is an essential component in this whole idea of transformation.

John and Jay had ideas about employment and job training. John said, "I'd like to see more consumers get trained professionally as counselors and therapists." Jay saw the information technology revolution as a great opportunity:

> I think no matter what job [consumers] end up with, it's going to be the biggest flex time opportunity they'll ever have. All other jobs are either full time or part time, and you have to be there on a schedule. If the schedule doesn't match the times that you're healthy, you've got a real problem. That's why a lot of mentally ill people do get jobs, but don't keep them that long, because they have to be there at a time when they are sick.

Sue's vision is that people

> will buy out of the system's concentrated efforts to convince them they are sick, wrong, morally and intellectually defective, useless, worthless, deranged and powerless. I envision labeled people throwing off the yoke of psychiatric oppression to establish alternative care projects, to build support networks and coalition, to grow in numbers and become a voice for sanity and common sense. . . I envision labeled people testifying before Congress and their state legislatures, demanding that psychiatric survivors be hired by the system to effect and monitor reforms. I envision labeled people filing lawsuits that will set precedent to make psychiatrists and mental health professionals think long and hard before prescribing one more Thorazine pill or one more contraindicated drug.
>
> I envision labeled people taking back their own lives and asserting their autonomy by refusing to have further dealings with a system that traumatizes the clients it is supposed to be helping. I envision labeled people writing their state and national lawmakers letters of protest, holding vigils, educating doctors and communities to counteract the lies and myths propagated by a mental health system that exists only to serve itself, to maintain and expand its own turf at the expense of societal diversity and the well-being of its clients (i.e., victims.) I envision labeled persons infiltrating the mental system, the legal system, the educational system to bring creativity and a sense of justice back to society at large.

And people weren't hesitant to share visions that involved changes on a societal level. Kris imagined a society where

> . . . a lot of systems would have to change, and money wouldn't be the god it is right now, and that influences everything. I would like

> to see the whole drug thing done away with altogether. Work would be set up so that people could have much more flexibility, be more connected, dance a lot, be spontaneous. Art and creativity would be valued and there would be many more places where the average person could do that. . . . All kinds of behavior would be considered alright. The gauge for a problem would be if the individual didn't like things and wanted them to change, then there would be a lot of help available. . .
>
> . . . In school we would be trained to listen to each other, trained in conflict resolution. . . . I think things would be really different if the educational system was changed. It's very antiquated right now, it's still stuck back in a military mode. . . . It would be very different, much less rigid, students would be able to learn at their own rate, there would be a lot more flexibility about when you accomplish certain tasks. . . There wouldn't be this weird kind of competition. I don't think that competition is necessarily bad, but not the way it exists now. I think if a lot of the pressures were off of people there would be a lot less mental illness.

Ava envisioned,

> A society that acknowledges the realities of the abuses that are happening within the world, mandates that people are held accountable and responsible for their actions, so that those people who are being abused do not internalize those abuses on themselves. A mental health system that is holistic, that does not pathologize the individual, but recognizes that pain and depression are normal human experiences, they are normal life experiences, that when somebody is feeling that kind of pain, it is a very normal response to what they are experiencing as being a living, conscious, in-touch human being on this planet where people are so out of touch. . . .
>
> Though I was actively trying to kill myself, I do believe that if we had systems in place where people, and political and societal systems, were held accountable for their actions, I don't think there would be mentally ill people walking around in the first place. So that's the root of the problem. But while we don't have that in place, I think for somebody like me who was suicidal, if I had a place I could go to that maybe was a locked environment, because I was really set on killing myself, but I mean a locked environment in the woods somewhere. I mean one that I chose, with spas, massage,

re-birthing, there was validation of my pain, there was a spiritual component. I probably really did need a locked environment, but I probably wouldn't have if society had taken care of the whole reasons why I got to be where I was in the first place.

10. CONCLUSION

While the concept of oppression was one that I worked with throughout my fieldwork, it was not necessarily the language used by my informants. Even so, their stories illustrate that oppression of people who are called mentally ill is pervasive in our society, and not limited to any one source.

While both survivors and consumers practice resistance through organized activities, they have different styles. Consumers tend to be activists on a more personal level, telling individual stories, and speaking out about specific professionals or persons who treated them without respect and in some cases abused them. Their political activism is directed towards media stereotypes of mental illness and government budget cuts that affect their ability to get treatment and assistance. Survivors, on the other hand, emphasize awareness of human rights violations within the mental health system. They approach these issues on a more political level, seek ways to change the structures and institutions they view as oppressive, and critique assumptions and approaches of the mental health system and the culture it is embedded in.

I saw several ways that survivor and consumer resistance strategies could complement each other. In his *Essay on Liberation*, Herbert Marcuse (1969:89) wrote, "The anarchic element is an essential factor in the struggle against domination: preserved but disciplined in the preparatory political action, it will be freed . . . in the goals of the struggle." This element can only be effective when it comes as the "result of enlightenment, education, political practice—in this sense indeed, as a result of organization" (Ibid 89). NAPA has never forgotten its roots as a radical, somewhat anarchic political organization that refuses to turn away from the societal causes and effects on madness. On the other hand, SOS provides a model of people who are speaking out and educating the public and the mental health system by telling their stories. They are breaking walls and barriers down on an individual level and at the same time speaking to large numbers of people. Carmen estimates that the group has directly reached over 12,000 people who might otherwise have never had a face-to-face encounter with someone labeled "mentally ill." The power to effect social change from this level should not be underestimated. The members of the group also support each other. In their regular restaurant get-togethers before or after presentations, they provide each other with the personal affirmation necessary to keep motivation high.

The political philosophy and strategies of NAPA and survivor groups like it were instrumental in the early days of the movement to push the mental health system into more of a partnership relationship with both survivors and consumers. These groups are equally essential now when there is a danger of being lulled into complacency because of apparent progress. The language of "empowerment" can be used to mystify the power imbalances that are still firmly in place. The best example of this came from an SOS member, John, who related his story about not being given an interview at a mental health agency which had encouraged consumers to reply. He said,

> They're not really ready to let me work in a position where I'm doing the same thing as a professional with a Master's. But there's been some job openings for positions for peer counseling, and they pay you like a peer, seven or eight dollars an hour. They don't want to pay me at a professional pay scale. . . It's left me believing that they don't really believe in what they're doing. They don't believe that they can help somebody get healthy enough to do what they are doing.

The abundance of critique from both groups about the medical model, whether at the personal or political level, leads us to seriously examine the consequences of emphasizing the medical model in dealing with madness. The effort to embrace biological causes and treatments of mental illness is seen by many consumers as a way to dispel the idea that mental illness is somebody's fault, or a weakness in character. The biomedical approach has worked this way for some of the people in this study, at some points in their lives. However, at other times, and for other people, it has had damaging consequences—physically, emotionally, socially, professionally, and economically. Consumers and survivors alike agree on that issue; consumers tend to see those incidents as individual and separate events, survivors tend to view them as part of a pattern of oppression.

From an anthropological perspective, the weakness in trying to make mental illness "just like" physical illness is that our culture holds deep-seated assumptions that body and mind are *not* alike. Even though it might be more acceptable and even fashionable now to be on psychiatric medications such as

Prozac, and celebrities like Patty Duke are publicly declaring their bouts with mental illness, for the majority of people this disclosure continues to carry real consequences; loss of job, social exclusion. In our culture, a broken mind is seen as far more dangerous and dysfunctional than a broken body. Mental illness is not a neutral term. As Thomas Szasz pointed out:

> Schizophrenia is a strategic label, like 'Jew' was in Germany. If you want to exclude people from the social order, you must justify this to others, but especially to yourself. . . . I am afraid that 'schizophrenia' and 'psychopathic personality' and many other psychiatric diagnostic terms mean exactly the same thing; they mean 'human garbage,' 'take him away!' 'get him out of my sight!'" (Szasz 1969:460)

Or, as one mental patient said, "If mental illness is an illness like any other, which I don't believe it is, the illness it most resembles is VD" (Chamberlin 1978:110).

Another limitation of the biomedical approach is that it tends to stop the dialogue on other roots of the problem. Even if there is a biological component to madness for some people, the consumers and survivors in this study tell us that it does not exist in a vacuum and is profoundly influenced by experiences of poverty, discrimination, and physical, sexual, and other kinds of abuses. Some of the people in this study found medications beneficial to them at some times, but survivors especially remind us that the use of medication should always be accompanied with the caveat that it may obscure the deeper social dimensions of the problem.

Another issue is the ethical responsibility that doctors have in making a diagnosis that brands someone with a label that is discriminated against. In the book *Medical Nemesis*, Ivan Illyich writes that

> . . . the physician acts primarily as an actuary, and his diagnosis can defame the patient, and sometimes his children, for life. By attaching irreversible degradation to a person's identity, it brands him forever with a permanent stigma. . . Like ex-convicts, former mental patients. . . are transformed into outsiders for the rest of their lives. Professional suspicion alone is enough to legitimize stigma, even if the suspected condition never existed. The medical label may protect the patient from punishment only to submit him to interminable instruction, treatment, and discrimination, which

> are inflicted on him for his professionally presumed benefit. (Illyich 1976:89-90)

I believe this situation, at the very least, obligates doctors to work towards educating the public in order to reduce stigma. But even more, as NAPA reminds us, they should also question the social consequences of labeling people. The people in this study said that discrimination worsens the condition of the patient and exacerbates whatever “illness” might be present.

In attempting to address the limitations imposed by a biomedical view on madness, some mental health professionals have created a category for “spiritual emergence.” Along with some of the survivors whom I interviewed, I find this solution to be problematic. As long as the category is still set in the context of the medical model, we continue to perpetuate a mind-body split, as well as a social oppression. By distinguishing a spiritual emergence from mental illness that is “biological,” we are again operating from a dualist perspective. Could the experience not be both biological and spiritual for the same person? How are people limited to the ways in which they can make sense of their experience when this dualism is imposed? There is also danger of creating a spiritual elitism. Who decides what constitutes a spiritual emergence? And how might this classification lead to complacency in questioning the treatment of and attitudes towards people with “real mental illness?”

I hope that this thesis has conveyed some sense of the complexity of this issue. Both survivors and consumers make it clear that there were times when they felt they were in severe mental and emotional crisis. As David said, “I certainly had problems, there was no doubt about it.” Survivors did not claim that they were not in crisis or did not want help but rather spoke out against the way their experience was pathologized and labeled, and the abuses that passed for help. They also pointed out the short-sightedness of current approaches and treatment for mental illness. The impact of a person’s behavior on the safety of themselves and others certainly needs to be considered, but the biomedical approach often obscures the potential to do so in a more liberating context. As Ava pointed out, she may have needed a locked facility to keep her from hurting herself, but it could have been in a more healing setting, and it might have been avoided altogether if abusers were accountable for their actions.

I believe this study offers many avenues for future research. I asked several people I interviewed what questions they thought were important that I hadn't asked. Responses included sexuality, body image, and weight issues (relevant for many people who take medications because one of the side effects is often a substantial weight gain). Another area I was unable to explore in-depth but is certainly worth investigating is the intersection between identity as a psychiatric survivor/consumer and other cultural identities, such as gender, class, and ethnicity. Several people in this study alluded to this issue: John as an African-American, Ava as a woman, and Kris around class identity.

I found my own views about mental illness and the mental health system radically shifted through involvement with these groups. I became acutely aware of how apolitical I and others can be when discussing the subject. I now find that I cannot see the words "mental illness" without placing quotes around them, as I no longer agree that the experience is an objective biological reality, at all times, for all people. Even more fundamentally, I question the power imbalance of a mental health system run by "normals," something I don't think I could have done while still embedded within the system, especially as a paid employee of it.

I found myself agreeing with what so many of the people in this research told me, summarized by Robert Fancher (1995) in his book *Cultures of Healing*: the criteria for decent and effective psychiatric care should be whatever works in the judgment of the person for whom it works. This seems like a simple statement, but true agreement with it would require changing the structure and composition of the mental health system, and more significantly, a shift of political and economic power in our society.

I hope this thesis has illuminated the resilience, humor, and courage that the people I spent time with displayed in their lives. What I learned, and have tried to convey, is that people called mentally ill do not deserve our pity, but rather our alliance in unraveling the systems of oppression which affect us all, mentally, economically, and spiritually.

In an essay that asks how the thoughts of Michel Foucault can be applied on an institutional level, John Caputo (1993:259) 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." As authors of knowledge, the role of the person with mental illness in our society would be completely different, and so would our perspective on mental health. I hope I have contributed something towards the creation of this healing gesture.

Ultimately, the dialogue that survivors and consumers are raising is *not* a debate about the cause of mental illness. It is rather a matter of emancipation and liberation from totalizing portrayals, and the effect they have on the lived experiences of people who receive the label of mental illness. Whether it is someone forced to get electroshock, told by a doctor that his anger is a symptom rather than a valid response to the situation, denied access to treatment she feel she needs, refused a job because of being labeled mentally ill, or avoided by people on the street because he is talking to voices that no one else hears, psychiatric survivors and consumers refuse to be quiet any more and demand that their rights and lives be taken seriously.

I have come to the conclusion that in our time and culture, madness can perhaps best be defined as having a vision that no one else shares. That vision could be one that psychiatry would call a delusion, or that the dominant culture thinks is "crazy"—if no one validates it, the person who experiences it can feel "mad," whether "mentally ill" or not. By this definition, madness is healed when the vision is shared, and through the process of resistance, survivors and consumers are sharing their visions with each other and the world.

THE END

It's been a long road. Joe and I have spent a lot of time together over the previous three years, a good five or six hours each week, going on errands to get groceries, apply for food stamps, cash SSI checks, wait for appointments at the mental health center. Joe has seen me sad and depressed about events in my life, tired from overwork on the job, and heard me nag him when he went off his meds. We sometimes go fishing together. We go to the grocery store each week. I know he loves strawberry shortcake and cauliflower with cheese sauce. I know how much his utility bills are because we sit down together each month to figure out his budget and pay them. I know how good he is with animals and kids. He knows my partner and me and sometimes comes to mow our lawn. He knows I have a hard time keeping my car clean and washes it once a month for five dollars (the deal is he gets the job if he's been clean and sober for at least a couple of weeks).

Ultimately, together we found a combination of circumstances that clicked for Joe: an apartment he felt safe in, a job he liked, and a few friends he trusted and could go fishing and hiking with. Sometimes he took his psychiatric medications, sometimes he didn't. What seemed to affect him the most negatively was smoking marijuana, which he tried hard to abstain from. He said he felt better when he stayed "clean and sober."

Before I left my job, we went on a fishing trip. The year before, Joe was there for my first attempt at fishing and taught me how to put a worm on a hook, so we both thought it would be a good way to mark the end of our working together. As we sat in the Oregon sunshine casting our lines out into the water and waiting for fish that never showed up, I shared with him how excited and scared I was to be moving to San Francisco and starting school. He told me that he would miss me. Then he glanced around the lake and told me that we had better be careful. "There are anaconda snakes in these waters." I looked at him and said, "Yea, but they're not nearly as dangerous as the hoop snakes."

"What are those?"

"You know, they put their tail in their mouth like a hoop and then roll really fast to get people."

He looked at me. We both smiled and winked.

APPENDIX

CONSENT FORM FOR TAPED INTERVIEW

I, the undersigned, have been fully informed of the study being undertaken by Maria Duerr, a candidate for the Master's Degree in Social and Cultural Anthropology at the California Institute of Integral Studies, and agree to a taped interview.

I understand that the tape of my interview will be used for educational purposes only, appearing in written form as a thesis and as part of presentations to academic and other interested institutions (mental health agencies, advocacy groups). No one else besides Maria Duerr will have access to this tape. Unless I specifically request otherwise, a pseudonym will be assigned to me for the purposes of protecting my confidentiality. I understand that I have the option to refuse to answer any question.I also understand that while Maria Duerr has the final decision in what will be included in her thesis, I may request to be shown a draft of any portion which contains material from my interview(s) and I may give feedback about the written material.

____
(name - please print)

____
(signature)

____
(signature of legal guardian, if applicable)

____
(date)

By checking here, I request that my real name be used. (If not checked, a pseudonym will be assigned) ____________

A Thesis in fulfillment of a Master's Degree in Social and Cultural Anthropology
Maria Duerr
California Institute of Integral Studies, San Francisco

Hi! Thanks for your interest in participating in my fieldwork. I have prepared this packet to give you more information about the interview itself and my thesis. If, after going through the packet, you would like to take part in an interview and/or have more questions or comments, please call me at 415-568-0912. You can call me collect if that is more convenient.

This packet contains:

- information sheet on the interview (this page)
- a short version of my thesis proposal (you can get the long one too if you're interested)
- consent form

THE INTERVIEW

How long will it take?
I would like to spend between one and two hours with you, scheduled at your convenience. I may also ask you to do a follow up interview as well, if you have time to do that.

Where will the interview take place?
Again, this is at your convenience. I can come to your home, or we can meet at a coffee shop or a park. Whatever feels most comfortable for you.

Is the interview taped?
With your permission, it will be taped as that is the easiest and most accurate way for me to remember what you said. But if you would rather not, we can do it without a tape recorder.

What kinds of questions will I have to answer?
First of all, you don't **have** to answer any question you don't want to (please see the consent form). My main concern is that you feel comfortable and safe. I am not a therapist and not affiliated with the mental health field in any way, so I am not looking at your answers from the point of view of assessing your mental health. What I am interested in is what it is like for you to live in the world as someone who is or has been labeled with a mental illness, and how you have chosen to speak out about that experience. These are some of the questions I am interested in:

- What term do you use to identify yourself: psychiatric survivor, mental health consumer, client, other, or none? What reactions do you have when you hear yourself called other terms?

- Describe what it is like for you to be called mentally ill - what kinds of reactions do you get from people, whom do you feel the most comfortable with, the most uncomfortable with?
- What are some experiences that have shaped how you think of yourself and your identity?
- Tell me about some incidents when you have felt excluded because of your identity as mentally ill. Describe any times when being labeled has been an advantage for you, i.e. obtaining disability benefits, in social situations, etc.
- What motivated you to get involved with this movement and begin speaking about your experience? What is it like to talk to the public about having a mental illness ?
- What strategies do you use when talking with people who do not know that you have been a patient or consumer - do you find yourself covering up at times?
- What strategies do you use to let someone know that you have a mental illness (or however you define it)? Would people think that anyway, and if so, how?
- What or who do you need to be careful of when revealing this information?
- How do you define mental health and mental illness?

Who will have access to this interview?
For the tape or the notes of the interview itself, I will be the only one who as access to that material. I will take these notes and incoporate them into my thesis, which will be given to my faculty thesis committee at the California Institute of Integral Studies. I would also like to present the findings of the thesis to other anthropology students, to other survivor and consumer groups, to mental health settings, and other interested parties. It is academic policy to give all participants in a study such as this a pseudonym, so your real name would not appear in the paper. However, I would also like to offer you the option for your real name to be used if you would like to view this as part of your speaking out about the subject (see consent form).

Will I be able to get a copy of the finished paper?
Yes, definitely! In fact, I would love your collaboration in the writing phase as well. If you would like, I will make available to you a draft of the section of the paper with your interview, and you can review it and give me feedback if there are any corrections or additions to be made.

Is there any reimbursement?
Unfortunately, I am not able to monetarily reimburse you for your time - I wish I had the capability to do that! What I can offer you is a good cup of coffee if we go out to a coffee shop, a copy of the finished product, and a promise that the project could be part of future advocacy efforts to re-evaluate current definitions of mental health and illness, to raise awareness about human rights violations

and discrimination against people with psychiatric disabilities, and to educate both the mental health field and the general public about the effects of stigma as personally experienced by survivors and consumers. I am actively seeking and would love to hear from you about places and ways to incorporate this work on these levels.

What does anthropology have to do with mental health?

Good question. Many people think of anthropology only as the study of foreign and exotic cultures, but it can also teach us a lot about our own culture. Mental illness and other psychologically-labeled phenomena are not often looked at through a cultural lens in our society. It is important to remember that here in the United States, the way we view “mental illness” and “mental health” is just as grounded in our own cultural assumptions as is the way, for example, most people in South American countries assume that it is natural to have a siesta in the afternoon. It is just that it is easier to see it as part of “culture” when it is *another* group of people. When we look at ourselves, it appears to be “just the way it is,” something that we all take for granted as the “truth” of the matter. The advantage to looking at mental health through anthropology is that it opens up a whole new world of possibilities for dealing with something we may never have thought we had any choices about.

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