Psychiatric Survivor Oral Histories: Implications for Contemporary Mental Health Policy

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Capstone Report

Prepared for:
Professor Joya Misra

Prepared by:
Oryx Cohen

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Center for Public Policy and Administration, University of Massachusetts, Amherst

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Introduction

> The "madman," as defined by others, is part of society's cultural heritage. Whether "madness" is explained by religious authorities (as demonic possession, for example), by secular authorities (as disturbance of the public order), or by medical authorities (as "mental illness"), the mad themselves have remained largely voiceless (Chamberlin, 1990).

In 1999, U.S. Surgeon General Dr. David Satcher announced that 22 percent of the population at that time had a diagnosable mental disorder, and half of all Americans will have such disorders at some point during their lives. According to recent studies, 5.4 percent of the adult population in the United States suffers from *severe* mental illness (SMI) during any given year, illnesses including schizophrenia, depression, and bipolar disorder (Kessler et al., 1998).[1] The number of "mental disorders" listed and defined in the Diagnostic and Statistical Manual (DSM) actually increased from 300 to 374 from DSM III-R to DSM IV (Caplan, 1995). Twenty years ago there were only 106 disorders identified (Herbert, 1998). The indirect costs of mental illness (e.g., lost productivity) were estimated at $78.6 billion in 1990. In 1997, $73 billion was spent directly on mental health services. Between 1987 and 1997, U.S. spending on mental health services grew by 4 percent (GAO, 2000).

Thus, while the U.S. has been steadily increasing its substantial mental health spending over the past few decades, the mental health "problem" seems to be getting worse, as according to the DSM, almost one fourth of Americans could be considered mentally ill. One way of addressing this apparent dilemma is to ask people who have

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[1] An individual is said to have a severe mental illness (SMI) when he or she meets the criteria for a DSM disorder during a 12-month period (excluding substance use disorders and developmental disorders) causing functional impairment. Functional impairment is defined as substantial interference with one or more major life activities including basic daily living skills (e.g., eating and bathing), instrumental living skills (e.g., maintaining a household and managing money), and functioning in social, family, and vocational/educational contexts (Kessler et al., 1998).

experienced the mental health system first-hand about their conceptions of “mental illness” and what works and does not work.

The perspective of ex-patients is usually left out of history books and the psychiatric literature, leaving explanations of the human psyche and evaluations of treatment regimes to the "experts." Relying on psychiatrists to critique mental hospitals or therapy techniques is akin to making teachers the sole evaluators of their classrooms. This study allows psychiatric survivors to describe in their own words their experiences with psychiatry. Because most of the study's participants have more or less "recovered," their stories can tell us much about what is effective and what can be improved in contemporary mental health policy.

Before delving into these 21st century personal histories, I take a cultural-historical approach to explore how conceptions of mental illness and well-being, treatment and recovery have evolved over the last half century. Specifically, I will discuss the push for deinstitutionalization, the medical model of mental illness, the consumer/survivor movement, and the recovery literature.

Deinstitutionalization

In the early 20th century, the public state mental hospital was the primary site for treating severe mental illness (Dickey, 1997; GAO, 2000; Frisman, 1989; Kamis-Gould et al., 1999). Widely circulated media reports in the 1940s and 1950s about the inhumane conditions in state hospitals featuring locked up, abused, and isolated patients provided the major impetus for massive deinstitutionalization. Other factors, notably the introduction of new psychotropic medications (such as Haldol and Thorazine), several important court decisions, and the Community Mental Health Centers Act of 1963, have contributed to a 90% decline in state hospital census since 1955 (Dickey, 1997).

For example, a Massachusetts court decision played a significant role in closing Northampton State Hospital. The 1978 decision in Brewster v. Dukakis required the development, funding, and execution of dozens of community programs so that patients could be treated in less restrictive settings (Smith College URL, 2001).

In more recent years, the rhetoric behind the push for deinstitutionalization has centered on two major premises: that newer medications have allowed mental health consumers to become more integrated into the community and experience a better quality of life, and that community-based care is more cost-effective (Kamis-Gould, 1997). In practice, cost considerations seem to be given more weight. Mental illness prevalence rates are increasing, and many in the mental health field fear that community-based programs are simply replicating hospital practices (Huskamp, 1999).

In fact, many argue that "deinstitutionalization" from state psychiatric facilities has just led to "reinstitutionalization" on wards at general hospitals and in nursing homes, with a heavier reliance on psychotropic drugs.[2] According to one estimate in the mid-1980s, nursing homes accounted for 29% of national expenditures on behalf of the mentally ill (Frisman, 1989). Given the continued exodus of mental patients from state institutions, this number has likely increased over the past 15 years.

A federally sponsored community program called the Program for Assertive Community Treatment or "PACT," now active in 26 states, prides itself as being a "hospital without walls." One goal of the National Alliance for the Mentally Ill (NAMI) is to have PACT programs in all 50 states by the year 2002 (Oaks, 2000). However, with their strong focus on medication compliance, many current and former patients view programs like PACT as a failure of deinstitutionalization, experiencing them as "wards in their backyards" (SCI URL, 2001).

Federal disability policy and recent court rulings reflect the continued need to integrate people labeled with disabilities with the rest of society. The historic 1999 Supreme Court decision in Olmstead v. L.C. upheld the Americans with Disabilities Act's integration mandate, requiring that patients be treated in the "least restrictive setting" and that interaction between those with and without disabilities be maximized (Bazelon Center, 2001).

To add further complexity, patients and ex-patients often find themselves in neighborhoods that are suffering from a lack of civic engagement and a breakdown of community. Membership in community organizations, voting, church attendance, and even such things as participation in bowling leagues have fallen sharply in recent years (Putnam, 2000).

McKnight (1995) argues that this increasing lack of civic engagement has led to an over-reliance on professionals and institutions. He asserts that professional institutions and service systems have effectively "colonized" communities, rendering neighborhoods impotent to solve their own problems (McKnight, 1995). For example, in the past family, friends, and neighbors were more expected to provide support people who just experienced loss or a traumatic event. With the advent of the "grief counselor," people who have gone through tragedy are more likely to be referred to "experts."

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[2] Critics of managed care point out that the more risk transferred to Managed Behavioral Health Care Organizations, the more likely that they will reduce services, forcing a shift from rehabilitation programs

McKnight argues that this type of specialization actually manufactures problems and undermines community capacity to take care of its own. Ironically, deinstitutionalization, supposedly a step toward community, has been accompanied by an increasing reliance on institutional structures. These institutions and the professionals that represent them generally view "mental illness" through the lens of the medical model.

The Medical Model

The medical model currently dominates the mental health field. The model defines mental illnesses as “brain diseases” similar to diabetes, heart disease, or cancer. For example, the medical model suggests that clinical depression results from a deficiency in the neurotransmitters serotonin and norepinephrine in the synapses between neurons in the brain (Breggin, 1991). Mental health organizations such as the American Psychiatric Association (APA), the National Institute of Mental Health (NIMH), the National Alliance for Mental Illness (NAMI), and the National Depressive and Manic Depressive Association (NDMDA) subscribe to the medical model (Breggin, 1991). Medical schools train psychiatrists as medical doctors, teaching them that mental illnesses are no different from other physical ailments.

It should be noted that not every mental health professional subscribes to the medical model. Many psychiatrists, psychologists and counselors view "mental illness" as the result of social, biological, environmental, interpersonal and other factors. This discussion focuses on hospital psychiatry, where the medical model tends to dominate more than in outpatient settings. However, three of the current study’s participants were

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and therapy to a heavier reliance on psychotropic drugs (Huskamp, 1999).

solely outpatients and still encountered therapists and psychiatrists who worked primarily within the medical model.

The medical model gained momentum in 1990 when President Bush signed a resolution (created by NIMH) declaring the 1990s the "Decade of the Brain." In our society, descriptions of "broken brains" and "chemical imbalances" are common descriptions of mental illness. People diagnosed with schizophrenia, mood disorders, and other mental illnesses are viewed as having chemical imbalances in the brain treatable by neuroleptic, antidepressant, and mood stabilizing medications (Breggin, 1991; Neugeboren, 1999; Fisher & Ahern, 1999; Fisher, 1998; Van Hoorn, 1992). Under the current system, psychiatrists refer to the DSM to make a "scientific" diagnosis, and inform patients they may have to remain on psychoactive drugs for the rest of their lives to control the underlying "disease."

Three of the most prevalent "severe" mental illnesses are schizophrenia, bipolar disorder, and clinical depression (or unipolar depression). According to the APA, psychiatrists estimate that 1% of the population has schizophrenia, 1% has bipolar disorder, and 5% has unipolar depression at any given time (Ghaemi, 1997). For people diagnosed as severely mentally ill, the future seems bleak. Many mental health professionals view severe mental illness as a deteriorating condition that can only be controlled by using medications.

In general, psychiatrists prescribe a maintenance-based schedule of psychoactive drugs and occasional counseling, and have low expectations for their patients' chances of recovery (Fisher & Ahern, 1999; Fisher, 1998; Blanch et al., 1995; Breggin, 1991; Neugoboren, 1999; Reidy, 1994; Van Hoorn, 1992). For example, psychiatrists may tell their chronic patients not to expect to work again or pursue an advanced education (Lovejoy, 1982). Of the millions of Americans diagnosed with mental disorders, about one million are considered resistant to any treatment (Neugeboren, 1999). Is the situation so bleak for those people diagnosed as chronically mentally ill?

The following passage from Mead & Copeland (2000) illustrates the common experience for consumers:

> Recovery has only recently become a word used in relation to the experience of psychiatric symptoms. Those of us who experience psychiatric symptoms are commonly told that these symptoms are incurable, that we will have to live with them for the rest of our lives, that the medications, if they (health care professionals) can find the right ones or the right combination, may help, and that we will always have to take the medications. Many of us have even been told that these symptoms will worsen as we get older. Nothing about recovery was ever mentioned. Nothing about hope. Nothing about anything we can do to help ourselves. Nothing about empowerment. Nothing about wellness (Mead & Copeland, 2000).

In spite of the medical model's prevalence, there is limited evidence supporting its assumptions. For example, no biological marker for mental illness in the brain has been found as evidence of physical disease (Breggin, 1991; Neugeboren, 1999). Recently a movement has developed that highlights the possibility of recovery and proposes an alternate conception of mental illness that takes into consideration social, cultural, and environmental factors.

Despite the endorsement by the largest psychiatric organizations and the backing of a powerful pharmaceutical lobby, the medical model has been challenged by the same people that psychiatry had once written off. Ex-patients, or "psychiatric survivors," focus on self-determination and recovery, and attempt to redefine mental illness (Chamberlin, 1990; McLean, 1995, Van Hoorn, 1992).

The Consumer/Survivor Movement[3]

Led by those who refer to themselves variously as “ex-patients,” “consumers,” “ex-psychiatric inmates,” and “psychiatric survivors” the consumer/survivor movement has gained momentum over the past 30 years. The different uses of terminology can be confusing, but each term reflects a slightly different ideology. All of the descriptors commonly used—ex-patients, consumers, ex-psychiatric inmates, and psychiatric survivors—reflect a general distaste for labels like “mental patient” and “schizophrenic.” Members of the movement prefer people centered language (Chamberlin, 1990; McLean, 1995; Reidy, 1994; Van Hoorn, 1992). “Consumer” and “ex-patient” suggest identification with the current mental health system that more radical members of the movement would like to reject (McLean, 1995). Those who refer to themselves as “ex-psychiatric inmates” or “psychiatric survivors” feel as though they have overcome psychiatric oppression and distance themselves from the dominant paradigm (Chamberlain, 1990; McLean, 1995).

The first formal organization of a sustainable movement began in 1970 with the formation of the Insane Liberation Front in Portland, Oregon (Chamberlain, 1990). Since that time, several organizations have developed independently and have been gradually developing into a more comprehensive and unified network. Organizations like Support Coalition International (SCI), which sponsored the current study, the National Empowerment Center (NEC), and the National Association for Rights Protection and Advocacy (NARPA) have mobilized to advocate for the rights of consumers and survivors. The movement is international in scope. SCI is supported by more than 70

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[3] The consumer/survivor movement is also known as the consumer/survivor/ex-patient or "c/s/x" movement.

grassroots organizations in eleven different countries. Members of the movement protest what they see as clear evidence of human rights violations in the mental health field: forced drugging, forced electroshock, dehumanization, and the pharmaceutical industry supported "medicalization" of the system (Chamberlin, 1990; McLean, 1995; Van Hoorn, 1992; Blanch et al., 1995).

The consumer/survivor movement has been successful at not only providing advocacy and blocking legislation, but in creating progressive policies and alternative strategies as well. For instance, the consumer/survivor movement successfully allied with the disability movement to pass the Americans with Disabilities Act (ADA) in 1990. ADA includes a provision outlawing discrimination in the workplace of those people considered psychiatrically disabled (Chamberlin, 1990). In fact, one of the underlying strategies of people in the movement is to ally themselves with other civil rights movements representing those have been similarly oppressed: gays and lesbians, women, and minorities (Chamberlin, 1990; McLean, 1995).[4]

As well as providing an advocacy role, the consumer/survivor movement stresses self-determination of treatment and alternatives to medication. Leaders in the movement critique the mental health system's apparent "marriage" with pharmaceutical companies as not being in consumers' best interest. Currently, the amount of money drug companies such as Eli Lilly and Merrill Dow spend researching psychiatric drugs is second only to cancer research (Neugoboren, 1999). Psychiatry is relying more and more on the multi-billion dollar pharmaceutical industry to fund everything from scientific journals to conferences to research. For example, every year drug companies spend millions of

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[4] In fact, as will be discussed later, it wasn’t long ago that psychiatrists considered homosexuality a mental illness.

dollars to underwrite the American Psychiatric Association’s (APA's) national conference where their booths and ads are conspicuously on display. In fact, drug companies supply between 15-20% of the APA’s total yearly revenue (Breggin, 1991). And recently, the Program for Assertive Community Treatment or PACT was discovered to be funded by pharmaceutical companies through a slush fund created by the National Alliance for the Mentally Ill (NAMI) (SCI URL, 2001).

Consumers/survivors reject the medical model and argue that “mental illnesses” are a behavioral and biological manifestation of a complex interplay of social, emotional, and cultural stressors (Fisher & Ahern, 1999; Fisher, 1998; Neugeboren, 1999; Breggin, 1991; Chamberlin, 1990; McLean, 1995). The focus is on the individual person and his/her history, assets and struggles, rather than on a specific diagnosis. Activists believe that individual people require individual, self-determined strategies in order to be rehabilitated. Supporters of the movement view "mental illnesses" as temporary imbalances as opposed to physical diseases. They stress empowerment and recovery versus maintenance, hope versus resignation (Fisher, 1998).

Evidence for Recovery

Under the medical model, complete recovery is not a possibility. However, recent studies refute this notion, finding that many of those labeled as severely mentally ill do recover over time, especially when involved in programs that emphasize hope, optimism and potential (Fisher & Ahern, 1999). A longitudinal study that tracked more than 1,300 subjects originally diagnosed with schizophrenia over several decades found that one half to two thirds “recovered or significantly improved” (Neugeboren, 1999, p.250).

Recent studies have also found that recovery rates are better in programs that highlight optimism and hope for the future. In another study by Dr. Harding, the researchers compared similar rehabilitation programs in Vermont and Maine. They concluded that the distinguishing factor between the programs was Maine's emphasis on maintenance and stabilization as goals versus Vermont's focus on self-determination, hope, and human potential. The results showed that Vermont's program had a significantly higher recovery rate. The researchers attributed this difference in large part to Vermont's focus on empowerment and hope (Fisher & Ahern, 1999).

Other studies have compared traditional hospital environments to nontraditional community programs such as residential lodges and clubhouse settings. None of these studies have found traditional models to be more effective. In fact, the bulk of this research points to the superiority of nontraditional alternatives, especially in terms of cost and the promotion of independent living (Mowbray & Freddolino, 1986).

Several studies have compared medications to various "talking" therapies. However, these studies usually focus on improvement or reduction in symptoms as opposed to recovery. Psychiatrists and psychologists usually find middle ground and suggest that the best solution lies in some sort of combination of medications and psychotherapy.

However, there are limitations to these studies. Breggin (1991) found that there was strong investigator bias in studies of anti-depressant medications. Some researchers consistently find positive results, while other researchers have found that anti-depressants barely outperform placebos (sugar pills) if they outperform them at all (Breggin, 1991). Furthermore, many professionals, not to mention consumers or survivors, feel the negative side affects of medication may outweigh their benefits (Breggin, 1991). Also, talking therapies used in experimental designs don't accurately reflect those actually used in practice (Breggin, 1991). For example, it is difficult for subjects of an experiment to establish a rapport with their therapist when they are randomly assigned to a group. Neugoboren (1999) provides evidence that psychotherapy is often more effective than medications when individuals are allowed to choose their therapist because it enables people to have responsibility for their own recovery. Cognitive therapy that focuses on rationalizing irrational or paranoid thinking has proven to be especially useful in treating depression (Mondimore, 1999).

Although current research is limited, the recent push to focus on recovery has led to researchers attempting to operationalize the recovery process. Spaniol (1999) defines recovery as a process of adjusting one's attitudes, feelings, perceptions, beliefs, roles, and goals to achieve outcomes or achievements such as developing a support network, living in stable housing, working in a challenging job, contributing to the community, and having limited or no impairment in functioning. One commonality found throughout the literature on recovery is the importance of empowerment in the recovery process (Chamberlain, 1990; Chamberlain, 1997; McLean, 1995; Rogers et al., 1997; Reidy, 1994; Fisher, 1998).

Recently, leaders in the consumer/survivor movement have attempted to define empowerment so that it will have more meaning in the mental health field. These researchers find that defining empowerment as it relates to self-help programs can help evaluate these programs and guide future programs. Having decision-making power, access to information and resources, a range of options from which to choose, using assertiveness, having hope for the future, unlearning conditioning, learning how to express anger, affecting change in one’s life and the community, learning important skills, improving one’s self-image, and overcoming stigma are some of the important elements of empowerment emphasized in these studies (Chamberlin, 1997). Rogers et al. (1997) found that these elements can be broken down further into three major factors that constitute empowerment: self-esteem/self-efficacy, actual power, and community activism.

The focus on empowerment has led to the formation of numerous self-help groups and consumer-run alternatives. Banks (1997) discussed the power of self-help groups in terms of social capital. Consumer-run self-help groups establish a greater locus of control and increase social capital by allowing people with shared norms to pool resources. Thus, self-help groups are often a vehicle for recovery as members of the group share stories and provide examples of successful coping mechanisms (resources) that in turn lessen isolation. The non-hierarchical structure encourages people to define their own problems and determine their own solution strategies. Members of self-help groups are both providers and recipients of information. The current study will attempt to clarify notions of “self-help” and “empowerment” and their role in the recovery process.

What determines whether someone will recover or not? Is it possible to identify commonalities in the recovery process, or is recovery strictly an idiosyncratic phenomenon? What are these people recovering from? What are the policy implications of all of this? Few studies have focused on the process of recovery from "severe mental illness." The present study will attempt to approach some of these questions by analyzing stories of recovery. In doing this, the study will give a voice to those who consider themselves “survivors.”

Methodology

The current project analyzes interview and survey data the researcher collected while directing the Support Coalition International (SCI) Oral History Project from June 1 through September 1, 2001. The purpose of the SCI Oral History Project was to gather stories of experiences in the mental health system from the psychiatric survivor, or ex-patient perspective.

Participants

Thirty-six people participated in the study, most of whom consider themselves “psychiatric survivors.” Largely because of issues of stigma, this population is difficult to locate. Thus, I used purposive snowball sampling to gather participants. Contacts I knew in the psychiatric survivor movement referred me to other psychiatric survivors, who referred me to their contacts, and so on, until my sample had “snowballed” to an adequate size. The segment of this population that is easiest to find are those people who are open about their histories and are affiliated with advocacy groups and civil rights organizations like Support Coalition International (SCI). In fact, all of the referrals for the current study came from SCI and organizations that sponsor SCI.

Participant Demographics

General demographic characteristics of the thirty-six participants are listed in Table 1.

Table 1: General Demographic Characteristics by Age (in percentages)

	Gender		**Race**		**Education Level**[5]				
Age[6]	Male (n=20)	Female (n=16)	White (n=31)	Mixed (n=5)	HS (n=1)	SC (n=10)	C (n=13)	G (n=12)	**Total** (N=36)
20-30	5.56	2.78	5.56	2.78	0	0	0	8.33	8.33
30-40	5.56	5.56	8.33	2.78	0	5.56	2.78	2.78	11.11
40-50	22.22	19.44	38.89	2.78	0	16.67	19.44	5.56	41.67
50+	22.22	16.67	33.33	5.56	2.78	5.56	13.89	16.67	38.89
Total	55.56	44.44	86.11	13.89	2.78	27.78	36.11	33.33	100

From this table, it becomes clear that most of the study's participants are older, white, and well educated. 81 percent of the participants were over forty at the time of the study, 86 percent are white, and only one participant does not have at least some college experience. In fact, 33 percent of the participants have at least some graduate school experience. Furthermore, as can be seen in Table 2, most of the participants work full-time and make a decent income.

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[5] HS=High School or less, SC=Some College, C=College Graduate, G=Graduate School and beyond

[6] Age of participants as of August 1, 2001

Table 2: Work Status by Income

	Income in Thousands					
Work Status	<5 (n=2)	5-10 (n=6)	10-20 (n=5)	20-30 (n=9)	>30 (n=13)	**Total** (N=35)
Full-time	0	5.71	5.71	25.71	25.71	62.86
Part-time (PT)	0	2.86	0	0	5.71	8.57
PT/Disability	0	5.71	5.71	0	0	11.43
UE/Disability[7]	5.71	2.86	2.86	0	0	11.43
Retired	0	0	0	0	5.71	5.71
Total	5.71	17.14	14.29	25.71	37.14	100

63 percent of the participants worked full-time and made over $20,000, with 37 percent making over $30,000.[8]

In analyzing the demographic data, it becomes clear that most of the psychiatric survivors included in the study blend well with the dominant social order. Most of the participants are white, most work, and most are well educated and therefore, assumedly, fairly intelligent. These data are somewhat surprising because they are in direct contrast to other studies that have found “mental illness” disproportionately affects those who are poor and those who are homeless (GAO, 2000). However, the participant demographics make sense in that almost all of the participants have significantly recovered and many have distanced themselves from the mental health system entirely. Having an education, being white, and having an income may have helped these people on their road to recovery, because they were already accepted on some social dimensions. Another factor that deserves mention is that minority survivors, while out there, were simply difficult to recruit, which is not an uncommon problem among studies of this type (Cannon et al., 1991).

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[7] UE=Unemployed

[8] Although higher income categories could have been included, I was more interested in assessing whether participants had sufficient income to comfortably take care of themselves, as “mental illness” affects lower-

Because the bulk of the research took place in Oregon and California, 69 percent of the study's participants were from the west coast. All but one of the face-to-face interviews were with people who lived in Oregon's Willamette Valley or the bay area of California.[9] However, the e-mail survey did generate at least some response from all four of the country's major regions, as well as from other countries.[10]

In terms of marital status, 47 percent of the participants were single, 26 percent were married, 21 percent divorced, and 6 percent were widowed. Almost a quarter (24 percent) of the participants had children.

Recruitment Methods

In utilizing snowball sampling, three major strategies were used. First, SCI included a question on their membership survey asking, "Would you be willing to share your story with an SCI intern?" Second, several announcements publicizing the project were made on SCI listservs that include thousands of members. Third, SCI staff recruited project participants at SCI events and visits to local mental health organizations. Potential participants were told that the study's purpose was to gather stories of survival, recovery, empowerment, and self-determination from the perspective of the psychiatric survivor or ex-patient. Hundreds of people responded wanting to participate. Because SCI lacked the resources to interview all interested persons, the organization prioritized those individuals who were willing to attach their name to their story and have it published on SCI's web site. In the end, twenty-two individuals were interviewed face-

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income groups disproportionately. Only two of those making $30,000 or more were making more than $50,000 per year, a lawyer and a retired chemical engineer.

[9] The exception was a woman from Boston, Massachusetts, who I interviewed at a rally in Vancouver, British Columbia.

to-face, fourteen surveys were received (these included two people who were also interviewed), and four open-ended written submissions were received (including two people who also completed the surveys).

Two complementary methods were used in this study: semi-structured interviews and surveys.

Interviews

The study included twenty-two semi-structured interviews designed to allow participants to discuss their experiences with the mental health system in an open-ended manner. The first step in the interview process was gathering basic demographic information and a rough profile through SCI's "Fieldwork Datasheet" (see Appendix A). The fieldwork datasheet was adopted from New York State's Oral History Project and included brief questions about psychiatric labels received, psychiatric drugs prescribed, other mental health experiences, and recovery methods used. After gathering general information through the fieldwork datasheet, interviewees were given a list of preview questions that included two main questions, and several other sub-questions to reflect upon before the interview (see Appendix B). Directly preceding the interview, participants read and signed an informed consent and a release form (see Appendices C and D).

During the interview itself, the interviewer first asked two main questions: 1) Can you describe the process you went through in recovering from periods of intense emotional distress? And 2) Can you describe how you overcame human rights violations in the mental health system? Interviewees were ensured that they could share as much or

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[10] Two people from Canada and one person from Germany are included in the present study.

as little of their story as they felt comfortable. The main questions were purposely open-ended to allow interviewees to describe their experiences in their own words. Because one of the study's major purposes was to explore recovery dimensions, many of which have been identified in previous research, certain "probing" questions were used later in the conversation to direct the interviews (see Appendix E). However, the interviews focused on what participants felt was important, and not all of the probing questions were used during every interview.

The interviewer had a very active role during these interviews. A crucial part of the interview was to establish rapport and make interviewees feel comfortable talking about difficult and sometimes painful experiences. Because the interviewers were psychiatric survivors themselves, they shared this information and some of their history with the interviewees. The fact that the interviewers shared many of the same experiences as the interviewees undoubtedly led to more authentic answers. Of course, while the interviewers did disclose some of their experiences, recognizing the purpose of the study, they kept the focus on the interviewees and their stories.

All of the interviews were videotaped and audiotaped, and then transcribed. This study includes analysis of the transcribed interviews.

Surveys

An e-mail survey, composed of questions similar to those used in the interviews, was mailed to several hundred individuals affiliated with SCI. These were extensive, open-ended surveys (see Appendix F), fourteen of which were completed and returned during the course of the project. As with the interviews, the surveys included questions that attempted to address all possible dimensions of the recovery process.

Before implementing the final version, a pilot survey was issued to several SCI members via listservs. As a result of the pilot test, confusing questions were clarified, and several questions were added, modified, or eliminated completely.

Written Submissions

Four "free-form" written submissions were included in this study's analysis. The written accounts were received in response to SCI's call for psychiatric survivor histories. These autobiographical accounts ranged from 1000 to 1500 words and addressed many of the same interview and survey questions.

Data Analysis

The interviews, surveys, and written submissions were analyzed for themes. First, I extracted twenty-six sub-themes, such as the "importance of support" and "abuse of power relationships" from the raw data. I then grouped the sub-themes into four larger categories that capture most of these stories' important lessons: 1) Trauma, 2) Social Control), Internalized Oppression, and 4) Recovery.

Trauma

Many of the study's participants felt that their emotional problems could be largely attributed to childhood experiences of physical and/or sexual abuse. Those participants who were not abused as children still attributed their "symptoms" or altered states to distressing life events, such as a long move or a death in the family. Interestingly, all of the participants - including those who were currently in the system and those who did not feel they had emotional problems before encountering the system - reported experiencing traumatic events within the psychiatric system itself.

Abusive Treatments are a Modern Problem

Movies and popular books such as *One Flew over the Cuckoo's Nest*, which feature graphic depictions of such "treatments" as electroshock, straight-jackets, and the use of isolation chambers, present psychiatry gone awry. Psychiatry's "master narrative," the psychiatric history that is presented to the public, attempts to portray these treatments as barbaric remnants of an archaic past. According to the master narrative, electroshock is now "safer," and the advent of psychiatric drugs that target the "illness" has allowed thousands of former mental patients to be deinstitutionalized and lead more independent lives (Boodman, 1996; Dickey, 1997). The participants in this study shared experiences that contradict these points, showing that abusive treatments are still being used and that psychiatric drugs can sometimes do more harm than good.

One fourth of the study's participants received electroshock or "electroconvulsive therapy" (ECT) during the course of their "treatment." Only one of these people experienced ECT within the last ten years. Jody Harmon, a 45-year-old feral cat trapper/anti-psychiatry activist who experienced ECT in the early 1990s, provides evidence for its continued popularity:

> When I complained [about the medication], the doctors didn't listen. Soon a Corvallis psychiatrist intimidated me into receiving electroshock at the Oregon State Hospital in Salem, telling me it was the "up and coming treatment" for

> bipolar disorder. He threatened that if I didn't go through with it I would be permanently institutionalized.

As Jody's experience demonstrates, ECT has enjoyed a comeback of sorts in recent years, hailed as therapeutic for ailments ranging from depression to bipolar disorder to schizophrenia (The Schizophrenia Homepage, 2001).

In this study, only one person had anything positive to say about their experiences with electroshock. All the participants were either forced to receive ECT or coerced into trying it when they were too emotionally drained to speak up for themselves. The participants describe their experiences with electroshock as terribly frightening, traumatizing, extremely painful, disorienting, and causing memory loss.

Barb Greene, a 48-year-old Licensed Massage Therapist, recalls her experience with forced shock as a teenager:

> The shock treatments were not a positive experience. I spent a lot of years in therapy as an adult, not only from my family situation but also for the shock treatments . . . They put the electrodes on my temples, which were hooked up to a machine that had the voltage . . . I would wake up and have soreness from where the electrodes had been on my temple and I would have no memory. That meant that I had no idea of where I was or what was going on. It would take awhile to kind of figure out where I was, who I was and what was happening. Part of the plan of shock treatments is that they are supposed to knock out your memory, which it does . . . I still do not have all of my memory back from either my childhood or that period of time. For a long time I couldn't remember anything before the age of 12 . . . They don't tell people that you could have permanent memory problems after these treatments. I think the doctors tend to minimize the memory loss problems. It doesn't feel good to not know what you can't remember.

Eight other study participants had similar experiences with ECT, often losing substantial amounts of memory. In fact, one participant can't remember whether he had ECT or not, as a large portion of his hospitalizations still remain a mystery to him.

Only one participant in the present study had anything positive to say about ECT, and even he was not an avid proponent. Ralph Hoffman, a 59-year-old retired chemical engineer, recounts his experience with ECT after psychiatric drugs failed to improve his severe anxiety:

> So I began a number of electroconvulsive therapy treatments three times a week. Each time I did lose some short-term memory, but regained most of it in between so I can remember some details. I remember being taken over to the receiving area afterwards. I remember I was given anesthesia. I had no pain before, during or after the treatments. I was given total access and the staff was very courteous toward me. After the administration of these treatments, I personally did not notice any improvement, but I would really have to defer to the experts there as far as whether they noticed any improvement. After about a month, apparently they did notice some improvement.

A few weeks later, Ralph was able to return home to his wife.

There are some important differences between Ralph's case and the experiences of the other participants. Ralph was a chemical engineer and had substantial financial resources, he had a supportive wife, and he was willing to put his trust in the "experts." Thus, unlike the other participants, he received complete informed consent, could afford the most respected psychiatrists, and had a family member present to monitor the process. It is difficult to know whether Ralph would have made the same improvement (improvement that he didn't notice himself) without the ECT.

As I left the interview, I witnessed an interesting exchange between Ralph and his wife. As I was leaving, he told me, "Even though my wife was present, and the doctors informed me about ECT, I still feel as though I were coerced." His wife quickly responded in a maternal tone, "Now Ralph, you weren't coerced, it was always a team decision, you know that." This short conversation demonstrated that even within one's own family, not being respected or having opinions taken seriously can be a common experience for people labeled as mentally ill.

The positive feeling that some people, like Ralph, experience as a result of ECT is sometimes compared to a “head injury high” that can result from traumatic injury to the brain (Boodman, 1996). However, for all the participants who were electroshocked, and even in Ralph's situation, the ultimate decision to use a very dangerous and controversial treatment was made more by those in charge than those who would supposedly benefit.

ECT is not the only part of the current mental health system that study participants identified as abusive. 67 percent experienced forced treatment (either psychiatric drugs or electroshock), 72 percent experienced coercive treatment[11], 50 percent were physically restrained, 61 percent were placed in solitary confinement, and 22 percent experienced other kinds of physical torture or abuse at the hands of “caretakers.” Although each of these categories of experience deserves careful attention, it is beyond the scope of this paper to explore all of these issues in the depth that they deserve. For this study, it is sufficient to point out that these experiences occurred and were experienced as traumatic for the participants. Some of these categories of experience, such as the coercive nature of the system, will be explored in greater detail in later sections.

The next section will focus on a category of experience that affected 100 percent of the study’s participants during their time in the mental health system: the use of psychiatric drugs.

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[11] Coercive treatment includes bribes, threats, and any other manipulation short of physical force to convince patients to participate in treatments such as drug therapy and electroconvulsive therapy.

Psychiatric Drugs

With the medical model as the dominant paradigm, "mental illnesses" are viewed as brain disorders or chemical imbalances that can be effectively treated with psychiatric drugs or "medications." Thus, it is not surprising that each of the study's participants had at least some experience with psychiatric drugs, including the three individuals who were not hospitalized as inpatients. As discussed, the prevalence of psychiatric drugs as the preferred treatment can largely be attributed to the increasing influence that pharmaceutical companies have enjoyed the last few decades within the field of psychiatry.

What may be more surprising is that all of the participants, even the nine individuals who are currently taking psychiatric drugs, described their experiences with these drugs as traumatizing, painful, and having numerous unwanted effects. As a point of reference, psychiatric drugs can be split into four major classes: neuroleptics (also known as "antipsychotics" or "major tranquilizers"), antidepressants, mood stabilizers, and benzodiazepines (or "minor tranquilizers"). Table 4 provides examples from the past and present of psychiatric drugs that fit each of these classes.

Table 3: Examples of Psychiatric Drugs

	Year Introduced	
Drug Class	1950 - 1980	1980-
Neuroleptics	Thorazine, Haldol, Stelazine	Clozaril, Risperdal
Antidepressants	Elavil, Parnate	Prozac, Paxil, Wellbutrin
Mood Stabilizers	Lithium, Tegretol	Depakote, Neurontin
Benzodiazepines	Valium, Xanax, Ativan	Klonopin, BuSpar

Whether it was Haldol administered by forced injection, Depakote taken willingly, or a "drug cocktail" combination of many medications, study participants described their experiences with these drugs in graphic detail. Below, this study takes a closer look at participant's experiences with two classes of psychiatric drugs commonly prescribed for this population: neuroleptics and antidepressants.

Neuroleptics: The Major Tranquilizers

Neuroleptics, or “anti-psychotics” such as Haldol and Risperdal are often prescribed for people diagnosed with schizophrenia or bipolar disorder in an attempt to control behavior that is viewed as delusionary or "psychotic." As discussed previously, in the popular imagination, drugs in this class are often viewed as "miracle drugs" that allowed people to be deinstitutionalized and live more independently. However, the ex-patients that came forward in this study express an entirely different view, as many of the participants of this study have spent years recovering from the deleterious effects of these “medications.”

All of the participants described feeling extremely lethargic and "zonked out" while on these drugs, showing that the term "major tranquilizers" is an accurate euphemism. Donita Diamata explains what happened to her at a hospital in Portland, Oregon:

> The worst bout of them overdoing it on medication led me to be crawling around like an animal on the hospital room floor. I was actually in the hospital for a stomach problem, and after I had a bad reaction to some stomach medication, somehow I ended up in the psychiatric unit. I was so heavily dosed on a cocktail of Haldol, Luvox, Risperdal, and a couple of other drugs, that I was toxic. I couldn’t walk, couldn’t control my legs, and couldn’t see--other than hallucinations. I blacked out for two weeks, didn’t know who anybody was. When I started refusing the medications, they strapped me down to the bed. Then I was restrained and given an IV of Haldol, to keep it going. And they just kept it going continuously into my system.

This was not an uncommon experience for participants in this study. Often, they were drugged to a state of "total limpness." Of course, quiet and lethargic patients can make the job of psychiatrists and hospital employees "easier," but the therapeutic value of this type of drugging is highly questionable.

The major tranquilizers also have a number of other adverse effects, including muscle twitches/jerks, uncontrolled pacing, blurry vision, heightened sun sensitivity, dizziness, confusion, and reduced libido. Scott Snedecor, a 48-year-old county mental health employee, describes some of his experiences with neuroleptics:

> I remember these drugs having a number of unpleasant effects. They wanted me to ward work . . . and my muscles were so shot from the medication that I couldn't even mop the floor . . . I also had a dystonic reaction where I couldn't control my tongue and it would contract wildly. Another reaction that would happen was called akathesia. I would get very restless and I would shuffle forward and back . . . When I was on this stuff my IQ just crashed and burned! I went from being in the higher regions of intellect to having tremendous difficulty with relatively simple tasks . . . Because I was on these medicines, my creative stuff went down hill, which is part of the wholeness of who I am.

Scott went on to describe how he went from having excellent, 20:10 eyesight, to developing myopia after only a short time on Prolixin. Experiences like Scott's were echoed throughout the course of the project.

Perhaps the most noticeable and debilitating effect of these drugs is that they can cause tardive dyskinesia (TD) and a several muscular conditions related to TD. TD is a serious, sometimes permanent, neurological disorder that causes involuntary movements of the face, extremities, and/or trunk (TD National Association, 1997). Scott described two symptoms associated with TD: involuntary tongue contractions and akathesia - extreme restlessness often resulting in pacing or rocking back and forth uncontrollably. It is estimated that five percent of those consistently taking neuroleptics for one year and over twenty-six percent of those with six years of cumulative exposure will develop TD, resulting in thousands of new cases each year (TD National Association, 1997). The situation is made even more difficult for those diagnosed with "severe mental illnesses," who are often told they need to be on "maintenance" neuroleptics indefinitely.

Antidepressants

The most common antidepressants now prescribed are also known as SSRIs (Selective Serotonin Reuptake Inhibitors). The SSRIs include drugs such as Prozac, Effexor, Zoloft, and Paxil. The study's participants reported that the most common effect of these drugs were increased anxiousness and hyperactivity.

For Janine Bertram, a 50-year-old semi-retired consultant within the disability movement, one day on Zoloft was enough for her:

> When the designer drugs started coming out, Paxil, Zoloft, etc., I wanted to try them. My psychiatrist prescribed me Zoloft and it made me feel so anxious and speeded up, it was terrible. It was worse than taking diet pills.

Tony Lipinsky, a 50-year-old Consumer Employment Coordinator, reports having a similar and even more intense experience after switching from Effexor, which had stopped working for him, to Paxil:

> At that point they decided to put me on Paxil, which is yet another one of these SSRIs. It had a dramatic effect and an even better one. Within two to three days, I was on top of the world. I was Mr. Confident and was going to be president of the United States, after which I'd probably graduate to Pope and then God. That was the way I was looking at things as that was the effect that Paxil was having on me. It also had another interesting effect. I was down to about 3 hours of restless sleep when my normal sleep pattern was 6 to 8 hours of sleep a night.

Both Tony and Janine's experiences show how the effects of these drugs seem to mimic those of methamphetamine or "uppers." Although the feeling may have been highly enjoyable for some, it was temporary. Tony and the rest of the participants who used antidepressants reported that eventually the high wore off, leading to a pattern of increased dosages and/or prescription changes. None of the participants reported feeling that these medications got to the core of their depression.

In fact, two of the participants felt like one antidepressant in particular, Prozac, led to them having unprecedented suicidal feelings. Leah Harris, a 25-year-old activist who recently received her master's degree in political science, explains what happened to her at age 13:

> My psychiatrist was now talking about a new miracle called Prozac that would work when others had failed. I was so hopeful about Prozac that I vowed to stop flushing it down the toilet periodically and to take my medication faithfully. And yet, after a brief period where I felt better than ever, Prozac just stopped working. So my psychiatrist just kept upping my dose. Then a minor problem developed. Those green and white capsules made me so wired and hyper that I couldn't sleep at night . . . Within months after I was prescribed the drug, I began to experience brief periods of a mystifying and terrifying desperation. These were new urges to cut myself. The urges to self mutilate began to grow and develop into full-blown suicidal ideation.

Leah had never before had suicidal tendencies, but in the next few years she tried to kill herself three times, usually after what she described as "minor confrontations" with family members. Now a "well adjusted" adult, she believes it was the pills that drove her to be suicidal as a teenager.

Tony Lipinsky describes a similar experience with Prozac after seeking help for his depression a few years ago:

> [The psychiatrist] started me on Zoloft, which did not seem to have too much of an effect, either positively or negatively. I was fairly depressed. I had gone

> through several jobs in a period of a year while I was working with her. She then moved me to Prozac. Whether it is a coincidence or not I don't know, but 60 days after that became my first active desire to end my life by actively blowing my brains out.

Tony and Leah's experience do find support in that recent reports have linked Prozac and some of the other SSRIs to suicide and other violent acts (BBC, 2000). At the very least, the participants' experiences suggest that antidepressants seem to mimic the effects of methamphetamines or "uppers."

Besides having these behavioral effects, antidepressants and other drugs can have serious adverse effects on internal organs, especially the liver and kidneys (Breggin & Cohen, 1999). For example, Susie Irwin, a 32-year-old Consumer Peer Counselor, has to have her blood consistently monitored to make sure that her Depakote does not permanently damage her liver. And when Tony was having problems with his kidneys, he was told to stop taking his prescribed Effexor. Despite all of this, psychiatric drugs have enjoyed increasing popularity in the mental health system, especially in hospitals.

Increasing Reliance on Psychiatric Drugs

While patients in the 1960s and 1970s were not immune to multiple medication prescriptions, the absolute number of drugs prescribed has increased dramatically in recent years. For example, in 1997, retail sales of antipsychotic medication increased by 63 percent, faster than any other drug group (Bazelon Center, 1999). This makes sense considering the increasing influence of multibillion-dollar pharmaceutical companies such as Eli Lilly and Upjohn. Table 4 demonstrates this trend among the current study's participants.

Table 4: Medication Prescription over Time

	Total Number of Medications Prescribed			
Year Last in Hospital	<5 (n=10)	5-9 (n=11)	>9 (n=10)	**Total** (N=31)
Before 1990	22.58	25.81	12.90	61.29
After 1990	9.68	9.68	19.35	38.71
Total	32.26	35.48	32.26	100

Table 4 shows that people who were last in the hospital after 1990 were more likely to be prescribed large amounts of medications, with half of these individuals being prescribed ten or more medications compared to one fifth of those individuals last in the hospital before 1990. While this is a relatively small sample, these results do reflect a larger trend in the mental health system (Bazelon Center, 1999).

The numbers become more real when put in the context of actual examples. A few of the study's participants consider themselves to be "consumers" and do take psychiatric drugs voluntarily. However, even these people complained about the effects of these drugs, especially when combined into what is colloquially termed a "drug cocktail." Susie Irwin talks about her current emotional struggle and her experience being on five medications at once, Serazone, Seraquil, Depakote, Selexa, and Klonopin:

> Serazone, we just upped that because I'm having a really difficult time with my depression and . . . I don't know if that is working. I've been struggling for three months now and something's not clicking, that's the way I feel and I don't know if it's like something in me is wanting to give up or the medications . . . I had a really good one week and then after that it went back downhill. So then I followed instruction again and we put on a little bit of Selexa . . . I just started that so I don't know if that's quite working yet . . . Depakote. Depakote's great for my moods . . . If I'm not taking my Depakote I'll either be a very happy person or a very sad person. But I have gained so much weight. I mean, you're already depressed and I don't have the desire to really want to exercise. I don't have the desire to want to get up out of bed, so if you add another medication on to you . . . The doctor didn't say, well you're gonna gain weight on this medication maybe.

> But I know other people that have and it's just terrible. I hate it . . . So I don't like taking the Depakote at all.

In this snapshot, Susie expressed some doubts about her medication regime (she later admitted being addicted to Klonopin). However, she still "followed instruction" and maintained some hope that just the right combination of drugs might lift her out of this very difficult (and vulnerable) emotional state.

Tony Lipinsky, who is now on just one medication, describes his recent "drug cocktail" experience in less ambiguous terms:

> I sometimes was on Paxil, sometimes I wasn't. Sometimes I was tried on Depakote, Neurontin, Trazodone, this and that, that and this, but nothing worked . . . Before I came to the Renaissance Center I was a walking Dow Chemical factory in my blood stream.

Both Susie and Tony came to the mental health system in search of help, only to find their already difficult life situations complicated even further.

Retraumatizing the Traumatized

Many people enter the mental health system after experiencing traumatic event(s). In fact, recent studies estimate that between 40-60 percent of both inpatients and outpatients have experienced physical or sexual abuse as children (Herman, 1997). While some people undoubtedly find what they need in the mental health system, too many are *retraumatized* by a system that purports to help.

Pat Risser, a 48-year-old consumer advocate, reflects on his history of abuse and the effects of over 20 hospitalizations:

> The overwhelming feeling while being raped or battered as a child was one of helplessness. I went to the mental health system for help with my emotional distress and they responded by hospitalizing me and retriggering the trauma of helplessness. I fought the restraints and seclusion because it only served to retraumatize me with the same helpless feelings of immobility that was present when I was being raped by my step-father. The mental health system didn't understand and they continued to try and treat me with painful drugs and other things that didn't help.

Several of the other participants experienced abuse as children only to find few people within the psychiatric system who were willing to listen. Some of these participants noted that many of the staff at the hospitals and psychiatric wards were well intentioned, but trapped in a system that was more concerned with controlling difficult behavior than getting to the root of people's problems.

Other study participants were not abused as children, but experienced other events in their lives as traumatizing. For example, Tony Lipinsky was recently widowed and was having trouble holding down a job when he haphazardly encountered the mental health system after going to a depression screening on National Depression Screening Day in 1995 (a day sponsored by drug companies). As a result of active suicidal impulses (which were possibly caused by the Prozac itself) and a perceptive therapist, Tony was committed against his will. In the hospital, he experienced such abuses as forced drugging, restraints, and isolation before he was able to get out of the hospital and start his life anew.

The mental health system is currently constructed to encourage power relationships, which often leads to abuse of that power. As a culture, western peoples are taught to respect authority and listen to doctors and other well-educated persons. Within the medical model architecture, this means listening to psychiatrists and "complying" with medication prescriptions and other requests.

Although the abuse is not always obvious, these unequal power distributions create a relationship where one person's humanity is valued more than another person's humanity. Many of the study's participants complained that psychiatrists and therapists simply did not listen to their stories, but only cared about "symptoms," such as hearing voices or having delusions. This type of interaction fails to recognize that these symptoms are not only a biological manifestation, but are a result of a series of very real life events that often include physical and sexual abuse.

Social Control

Not everybody who encounters the mental health system feels they have been traumatized, or feels that they have experienced emotional distress or altered states.[12] Behaving in a manner that challenges current social conventions, thus creating discomfort in *other* people, is sometimes sufficient to lead to diagnosis and hospitalization. After all, it was as recent as 1974 that homosexuality was listed as a mental disorder in the DSM III (Caplan, 1995). Those with different sexual orientations are not the only people at risk of being labeled. People who do not work at conventional jobs or who choose to live alternative lifestyles, often find themselves in the "care" of the psychiatric system. For example, Jody Harmon never felt like she fit in. She preferred to live alone in the outdoors along the river, where she could enjoy the fresh air and the stars. She always

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[12] Although not discussed in this paper, many people encounter the mental health system as a result of improperly diagnosed physical problems. One participant who was diagnosed as clinically depressed, actually had severe medical condition called myalgic encephalomyelitis that caused her to be overly fatigued. Once treated for the medical condition, her depression went away.

found a way to survive, yet to outsiders she was viewed as a poor homeless woman in need of care.

Leonard Frank, a 69-year-old author/activist, recalls his parents' reaction when he decided to quit his real estate job and rely on his savings while focusing on his spiritual development:

> I became more and more interested in reading and studying, and less and less interested in real estate . . . I wanted to think of [the new ideas I was learning] not only as a new philosophy and a new approach to thinking, but as a new approach to living as well . . . So I became a vegetarian, I became a devotee of the principle of nonviolence, and I became much more scholarly than I had ever been before . . . My parents visited me on a number of occasions. They didn't appreciate the changes I was going through . . . I felt I was becoming a better human being as a result of these changes . . . They were very concerned . . . They urged me to see a psychiatrist to get some help . . . [Eventually] they insisted that I see the psychiatrist. And when I wouldn't, they sent the psychiatric police to my apartment and arrested me.

At the hospital, after refusing to do things like eat meat or shave off the beard he had grown for religious purposes, to act "normal" in essence, he was subjected to a total of 85 shock "treatments" - 50 insulin coma treatments and 35 electroconvulsive treatments. Upon his release from the hospital a year later, he no longer remembered that John F. Kennedy was President, and it would take years of dedicated work to rebuild some of his memories and relearn what he had read in those books that had so inspired him.

Coercive Nature of the Psychiatric System

Unfortunately, experiences such as Leonard Frank's are not just tragic remnants of an archaic past. As discussed previously, "mental illnesses" disproportionately affect the poor and the homeless. In the 19th century, psychiatry labeled African slaves who wanted to run away as having "Drapetomania," a mental illness (NEC, 1999). In present day society, people like Jody Harmon and Leonard Frank, who "drop out" of society and choose to live an alternative lifestyle, are more likely to be labeled mentally ill. Of course, there are hermits and “street people” who manage to avoid psychiatric hospitalization and live in relative peace. However, if people are behaving eccentrically and/or making neighbors or family feel uncomfortable, the chances of being transported to a psychiatric ward against their will increase, especially if they lack a support system.

For example, when Jody was living alone along the river, she got angry one night and started yelling at a boat that was passing by. This attracted attention to herself and she was eventually committed to a mental hospital involuntarily. Conversely, if Jody chose to work 12 hours a day as a dishwasher and never uttered a word to anybody, yet was totally miserable, people may have left her alone.

Don Weitz, a 70-year-old anti-electroshock activist, explains why he was "locked up" and shocked:

> I think the main reason they gave me shock was because I was openly angry and rebellious. I was angry at my parents with good reason: they had pushed their upper middle-class values down my throat for so many years. I had swallowed these values and now, according to them, I was "mentally ill" or "schizophrenic" - not angry.

Although Don would probably not be considered low-income himself, the fact that he rejected his family's upper middle-class values placed him in a vulnerable position.

Once in the hands of the mental health system and labeled as mentally ill, the study's participants entered a different world where coerciveness and manipulation are the rule rather than the exception. Joe Balleta explains:

> My problems were also compounded by the attitude of those people in the mental health system. No one tried to understand me as an individual. They assumed that most people in the system were brain dead, retarded, and had no potential.

People who seek help in the mental health system, like Joe, usually receive a barrage of psychiatric drug prescriptions as a “first line of defense.” The lengths that many mental health professionals and community members will go through to ensure "compliance" are striking. For example, Western Massachusetts' chapter of the National Alliance for the Mentally Ill (NAMI) recently published a brochure entitled "How To Help Someone Who Resists Taking Medications." One of the tips they advocate is to "if warranted, connect medication compliance with continued community involvement; if necessary, try linking medication use with activities the patient needs such as obtaining spending money." Thus, a respected advocacy organization in the field of mental health promotes bribery as an effective way to deal with those people who society believes cannot care for themselves.

Tony Lipinsky describes his experience after becoming frustrated that none of his medications were working:

> Finally I got so disgusted with them that I just said I want out of your program and they wanted me out too. It was a mutual type of thing. So I basically was homeless. That meant I couldn't have the shared housing because I wasn't part of the program, and I wouldn't follow their instructions in terms of the medications.

By attaching medication compliance to basic needs, such as housing and food, the mental health system helps control a population that the rest of society views as irrational, difficult, and possibly dangerous.

In several cases, participants' altered states were brought along or assisted by chemical substances such as illegal drugs or alcohol, leading to "dual-diagnoses" of mental illness and chemical dependency. Ironically, while condemning drug addictions, the mental health system actively encourages dependency on powerful psychiatric drugs. Many of these drugs, such as Ritalin, the “minor tranquilizers,” and some of the antidepressants, produce such an intense feeling that they are sometimes used illegally for recreational purposes. Several of the study's participants described how addictions to alcohol or illegal drugs were in effect replaced by “medications”.

Susie Irwin describes how she transitioned from one type of drug to another:

> I just started getting into the system because I really started using [illegal] drugs heavily and was homeless . . . I hooked up with a clinic in San Francisco and that's when I first got on meds.

It is interesting that during the interview, Susie described this transition as if it were a positive step. This reflects the value that society places on different drugs depending on whether or not they are politically and socially sanctioned. Attempting to view Susie's situation objectively, it is difficult to say whether she was better off addicted to illegal drugs or being prescribed five different psychiatric drugs, one of which is a minor tranquilizer to which she openly admits being physically addicted. Unfortunately, although fully capable of making her own choices, Susie did not make decisions about her drug use without yielding considerably to the “expertise” of mental health professionals. Her psychiatrists and doctors, who depend upon pharmaceutical dollars for their livelihood, seem to have influenced these important decisions tremendously. As the next section addresses, many of the participants received this type of advice without being fully informed about the dangers and side effects of psychiatric drugs.

Loss of Rights

The study’s participants found that once they got into the mental health system, especially after being hospitalized, it was difficult to get out. After being hospitalized and diagnosed with a mental illness, participants lost their right to make their own decisions about treatment, to come and go as they pleased, and to be fully informed about treatment options and treatment effects. Many participants felt like they were effectively thrown out of the human race.

Carol Patterson, a 47-year-old program coordinator at the Independent Living Center in San Francisco, approached the mental health system in search of help and was shocked at what she found:

> I finally decided to voluntarily check myself into a hospital. I was given very confusing information when I was admitted. For example, one of the staff came in and told me that there was a hamburger stand around the corner. Well, I went looking for it and the closest thing I could come up with was a small kitchenette! I really felt the orderly was playing with my head. I finally realized that I was in a locked ward, even though I had entered voluntarily. So I asked to leave. The staff told me that I had to speak with my doctor, but he wasn't around. I felt they were being evasive and I started to scream. It was then that I was forcibly drugged and sent to my room. If it wasn't for my family, I don't know how long I would have been forced to stay there.

Several of the other participants had similar experiences where they voluntarily checked themselves into the hospital only to find getting out extremely difficult, especially without support from the outside.

For children, the situation is often bleaker, as they effectively don't have any rights until they are 18. Leah Harris explains how she finally got off psychiatric drugs at age 18 after doctors began prescribing them to her at 6-years-old:

> I was given the drugs as a child so it was always coercion, if I said I didn't want the drugs it meant that I was not cooperating with my treatment plan. Especially as a child and a teenager, you can't fight these things, even though your gut is telling you it's wrong. Nobody will listen to you. I claimed my rights when I was 18 and could refuse medication legally. How wrong it all was I wouldn't realize until over a decade had passed and I began to educate myself about the psychiatric survivor movement. Now that I look back, I think it's obscene that a traumatized little child would be drugged up. It makes me sick.

Unfortunately, experiences like Leah's have become even more common in recent years as more and more children are being prescribed drugs like Ritalin at younger and younger ages. Between 5 to 6 million children are currently taking Ritalin or Ritalin-like drugs. In the past ten years there has been a three-fold increase in prescriptions for two- to four-year-olds, even though these drugs have never been approved as safe or effective for children under five (Frisch & Sisson, 2001).

For children and adults alike, another way the mental health system exerts control and compliance is by not providing full information about the effects of treatments such as psychiatric drugs. For example, Susie Irwin mentioned that the doctors did not warn her that Depakote can lead to increased weight gain. Without having informed consent, patients often attribute the unpleasant effects of the drugs to personal fault or to the diagnosis itself. Often times the effects of these drugs can even mimic symptoms of mental illness. Tony Lipinsky's experience illustrates this point:

> The first night at the hospital they medicated me with Trazodone to make me sleep because I was very agitated. The next morning . . . [the doctor] prescribed the antidepressant Effexor . . . Interestingly, within three days, they had a dramatic effect on me. I moved from directly from being agitated, fearful, and withdrawn to very positive. You might say I was slightly intoxicated. I really did not give a damn . . . Unfortunately it did not stop there. I became more manic . . . which they then medicated me with more Trazodone to counteract.

Inducing manic episodes, uncontrollable highs associated with bipolar disorder, is one of many common effects of antidepressants, especially the SSRIs (Breggin & Cohen, 1999). Study participants were often prescribed multiple drugs to counteract the effects of other drugs, without being fully included in the process.

In order to have true informed consent, patients need to be informed not only about their rights and treatment effects, but they also need to be informed about all treatment options. The options presented to the study's participants were limited, with a strong emphasis on "drug therapy." Even when participants expressed a desire to try alternatives such as yoga, meditation, or acupuncture, their wishes were often ignored.

Kris Yates, a 51-year-old Marriage and Family Therapist, describes what happened to her when she returned to the United States after spending several years in the Middle East and being forcibly electroshocked in India (after being wrongly accused of stealing):

> I'd been in Asia and North Africa, completely different cultures. I flew basically non-stop from India to New York City after having just been released from the mental health hospital and having received electroshock, not to mention lots of drugs . . . When the man [from the Department of Health, Education, and Welfare] came to see me the next day, I said I wanted to see an acupuncturist because I knew I had problems. He said he would take me to a doctor. He took me to Staten Island Hospital and took me to a locked ward.

After realizing where she was, Kris panicked and was subsequently drugged against her will and placed in a padded room. It would be days before she would get out and find the help she needed.

Getting Out: Playing the "Good Mental Patient"

Given these experiences, how do patients manage to leave the psychiatric system? Many of those in this study were told that they have a severe mental illness, would never work again, and that they need to be on psychiatric drugs for a lifetime. Some checked themselves into a hospital voluntarily only to find that they couldn't leave.

Study participants found the easiest way to get out of the mental hospital was simply to cooperate with authorities and play the "good mental patient." Playing the good mental patient means adhering to current social conventions, complying with medications, and obeying all other orders. To get out, mental patients learn how to play the game. Leonard Frank was forced to shave his beard and eat food that included meat products. He took his neuroleptics like he was told, and eventually he was released. He hated doing it, the drugs clouded his already shocked brain even further, but he figured it was his only chance of getting out. Like many of the other participants, once out of the hospital he soon went off his medications and didn't look back.

Kris Yates explains how she got out:

> I got out of this hospital by becoming really passive. I became the good girl as quickly as I could. I said that I really would like to go to my family. I figured that part out. And I really do believe if I had said that initially when this man [from the Department of Health, Education, and Welfare] met me at the airport, I would have skipped the second hospitalization.

Unlike medical hospitals, where people are usually released when they recover or feel substantially better, those in this study were only released from mental hospitals when they agreed that they were “mentally ill” and agreed to adhere to "appropriate" biomedical treatment. This message was often so strong that it was internalized, leaving ex-patients struggling to regain their confidence and sense of self-worth.

Internalized Oppression

Too often, part of agreeing that one is mentally ill means recognizing that one is unreliable, deficient, and incapable of challenging work. After being diagnosed, even those who once excelled at school and have obvious intellectual capacity were sometimes told that the "illness" precludes having such things as a meaningful career.

Mike Hlebechuk, now the 41-year-old director of OCTA (Oregon's largest consumer-run mental health organization), spoke emotionally about some of the harmful messages he encountered after 20 hospitalizations and over two decades in the psychiatric system:

> During those years, over two decades that I was in the mental health system, there were some people who were working very hard to help me. But there were other people who, though I believe they were trying to help, I can wonder why they did what they did. Why did the doctors tell me - an intelligent, gifted person - that I would never work, would never get through school, would be on medications for the rest of my life, and should stay on social security disability indefinitely?

Inevitably, these demeaning expectations were internalized to some extent, sometimes leading to broken spirits and unrealized dreams. Happily, after years of searching, Mike finally found a way to move on after being physically abused as a child and experiencing a long, often traumatic trip through the mental health system.

Although many people do find a way to rebuild their lives, others internalize these negative perceptions, sometimes leading to a life of dependency on the system. It can sometimes be easier to accept a disability check, live in agency sponsored housing, and become a regular at a local day program that provides a TV, game room, and free meals, than to go back to school or look for work. In fact, the system is set up in a way that encourages this type of dependency, as going back to work can cut into disability checks.

Pat Risser explains how he was effectively brainwashed in the system:

> I was a good mental patient for several years. I was compliant and I searched for answers to my emotional distress. I tried everything the psychiatrists and therapists told me to do . . . Looking back I realize that I had been sort of brainwashed by the psychiatric system to helpless, hopeless and overly dependent.

It wasn't until Pat developed a support network of psychiatric survivors, many of whom had also been abused as children, that he was finally able to gain control over his own life. A mental health system designed for experts and service professionals to "fix" people from without is a system that encourages dependency. But as Carol Patterson put it, "you can't heal me without my cooperation, you can't."

Even after leaving the hospital and being cleared for reentry into society, many participants found a difficult road ahead. Several participants were ashamed of their mental health histories and felt like others would not understand. Leah Harris describes how she feels as a recent psychiatric survivor:

> I am ashamed to tell anyone, even my close friends, about my past and the significance of mental illness in my family. I am definitely not “out.” But I am taking steps by writing about my experience and reaching out to other survivors, as well as educating myself about the psychiatric survivor movement. I don’t feel comfortable sharing [my history] with anyone except other survivors. I am puzzled, embarrassed, and ashamed because of my past.

Leah later shared that she believes she has internalized the stigma that comes with being labeled as mentally ill. Like many other survivors, she feels she is in a constant struggle to overcome feelings of inferiority and isolation from other people.

Sometimes the stigma of society not only leads to internalized oppression; it also manifests itself in the form of outright discrimination. Carol Patterson reported that she was discriminated against when applying for a job:

> One time I applied for a job at a company I had successfully worked for in the past. I knew the systems and procedures; it would have saved them from having to fully train me. But on the application they asked if I'd ever had a nervous breakdown. I was naïve enough to answer the question truthfully. The person who accepted my application looked at me strangely and I knew I had been "round filed." They said someone would call me, but they never did.

Several other participants reported similar experiences when applying for a job. It was as if their experience in the mental health system disqualified them from all but the most menial of jobs. Many participants learned how to hide their histories in order to find employment. And many reported finding a meaningful job as integral to their recovery process, the topic of the next section.

Recovery

Most of the study's participants described their recoveries from "mental illness" and/or abuses they encountered in the mental health system as a process. A few participants felt as though there was nothing to recover from, and some felt they had made "complete" recoveries. As discussed previously, the literature suggests that the recovery process leads to outcomes such as developing a support network, living in stable housing, working in a challenging job, contributing to the community, and having limited or no impairment in functioning (Spaniol, 1999). In this sense, the majority of the participants have made significant recoveries. Most participants are working, many have found support within the consumer/survivor movement or elsewhere, many think of themselves as "activists," and most have found effective ways to cope with life events and have little or no problem with psychiatric "symptoms."

Table 5 shows that most of the participants have been out of the hospital for more than five years after being diagnosed with severe mental illnesses such as schizophrenia, bipolar, and depression.

Table 5: Diagnosis by Years out of Hospital

	Years out of Hospital		
Diagnosis/ Label	1-5 (n=7)	>5 (n=26)	**Total** (N=33)
Schizophrenia	3.03	27.27	30.30
Bipolar	3.03	12.12	15.15
Depression	3.03	0	3.03
Schiz/Depression	0	6.06	6.06
Schiz/Bipolar	0	6.06	6.06
Schiz/Multiple	9.09	18.18	27.27
Multiple[13]	3.03	6.06	9.09
Other	0	3.03	3.03
Total	21.21	78.79	100

Most of the participants (70 percent) were diagnosed with schizophrenia (either by itself or in combination with other disorders), a disorder that is considered especially resistant to treatment (Fisher, 1998). About half of the participants were diagnosed with more than one disorder. The average participant was hospitalized 6 times. Despite all of this, they have made significant recoveries. How were they able to do it?

No Magic Bullet: Multiple Recovery Methods Worked

Figure 1 shows that participants attributed their recoveries and improved sense of well-being to a number of important "recovery methods."

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[13] Multiple diagnoses, not including Schizophrenia

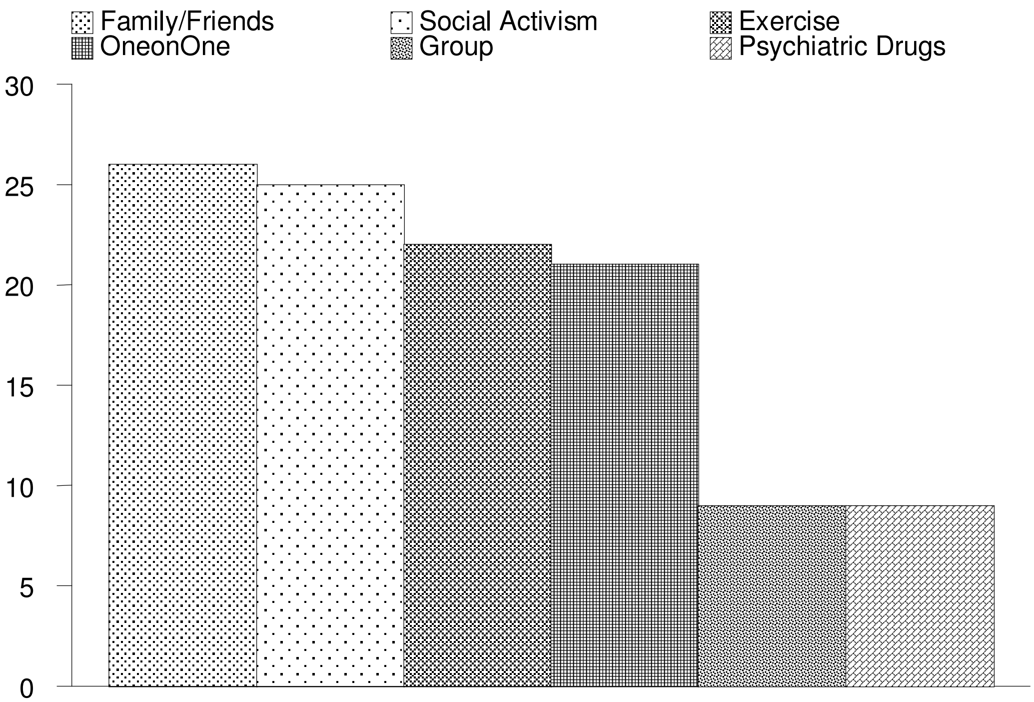

Figure 1: Participants Used Many Recovery Methods (N=36)

Figure 1 indicates participants' most common recovery strategy was the support of friends and family (at 72 percent). Social activism, exercise, and one-on-one therapy were also commonly reported (69, 61, and 58 percent respectively). Group therapy and psychiatric drugs were only reported by 25 percent of the participants.

Given the difficulties that participants experienced with psychiatric drugs, it is not surprising that only a fourth felt they assisted in their recovery process. This also happens to be the number of people currently taking medications, and with just two exceptions, the people who felt medications helped were those who were currently taking them. Most of the participants who are using psychiatric drugs use only one or two drugs, and many express a desire to eventually get off the "meds." For example, after finding a place that would listen to his "drug cocktail" complaints, Tony Lipinsky is now on just one medication of his choosing, Wellbutrin.

Viveca Walnum, a 47-year-old office assistant, describes her feelings about being on Prozac:

> Prozac helped me return to a place of no depression. Before taking Prozac I was always slightly depressed. I will say that if I could find a way of getting off the drugs without becoming depressed or manic I would do it.

Although she does feel that Prozac has helped her, Viveca does want to find a way to get off of it. Viveca's experience also shows that different people can react in very different ways to the same drug, as other participants described how they felt Prozac triggered manic episodes and suicidal thoughts.

While most of the study's participants tended to reject institutional treatments such as psychiatric drugs and group therapy, it is interesting that many reported one-on-one therapy as a recovery method. Most of these people had both "good" and "bad" therapists, but usually "one good therapist" stood out as especially helpful. Participants described these therapists - whether they were psychiatrists, psychologists, or other professionals - as people who were perceptive, who listened, and who treated them with respect. Susie Irwin describes her relationship with her favorite therapist:

> I was really worried when I switched from Network to Unity because I had one of the best therapists I have ever had at Network and I didn't want to lose that. This therapist was really honest and easy to talk to. In the way she would help me, it was more me discovering what was going on than her saying well this is what it is.

Carol Patterson had a good experience with an intern on the psychiatric ward:

> I remember one intern in particular who really listened to me. I guess she hadn't been there forever and wasn't burned out yet. Well, she gave me a sense of hope and made me feel like I really wasn't much different than she or anybody else.

This interaction stuck with Carol and eventually she was able to regain control of her life. Many of the participants recalled meaningful interactions with therapists or friends that they could fall back on and that continued to give them strength.

As Figure 1 indicates, it wasn't one "magic bullet" that “cured” these people. Instead a combination of strategies and circumstances allowed participants to improve their sense of well-being. Along with the importance of having support, participants indicated the importance of things like diet, reading literature, and spirituality.[14] Perhaps most importantly, for the majority of participants there came a time when it "all clicked," when they realized that nobody was going to recover for them, they were going to have to find a way to do it themselves.

Empowerment

"Self-help" was most common recovery method reported, as 94 percent of the participants indicated they used this strategy. Self-help is not included in Figure 1 because in this study "self-help" encompasses multiple recovery methods, which may include traditional self-help groups *and* other strategies such as diet and meditation. The prevalence of self-help indicates the value that participants' placed on feeling empowered to make their own decisions.

Participants' experiences with empowerment reflect all three components of empowerment identified by Rogers et al. (1997): self-esteem/self-efficacy, actual power, and community activism. In order to get out of the hospital and "start over," the participants developed newer and more positive conceptions of themselves and their abilities to solve problems.

Jody Harmon talks about how she took a proactive stance and started feeling human again:

> If there was a good thing to come out of [the physical abuse in the hospital], at least that abuse created a fighter out of me - I will never take abuse again from this system of coercion and dependency. So I didn't win my rights - I stood up and demanded them. For awhile the system had convinced me that I wasn't fully human and didn't deserve any rights. Well, I learned how to use the internet two years ago at the library and suddenly found that there were other people who had gone through similar things, who were also abused and ostracized. Here were some people who listened to me and actually understood when I talked. I started feeling like a human being again.

After nearly being beat to death by hospital staff, Jody decided it was time to take action. This action led to her finding people who validated her experience and helped to improve her damaged sense of self.

Mike Hlebechuk discusses how action's like Jody's can have *actual power*, leading to real changes:

> In 1987 I started to prove the doubters wrong. I was elected the first President of the Board of Directors of Mind and Power, Inc., which I believe was the first totally consumer-run agency in Oregon. At that point I decided for the first time in my life that, rather than letting the mental health system dictate my life choices for me, I was going to make my own choices about my treatment and how I would conduct life. When I did that, personal power started coming into my life. From 1987 through 1997, I was only hospitalized 3 times. Prior to that I was hospitalized 17 times. Now, you can do the math, but my life was getting a lot better since I decided that I was going to take care of myself and make my own decisions.

Like many of the other participants, Mike's change in thinking endured over time, creating a positive cycle of change. As Mike felt better about himself it also affected how other people viewed him. Having more respect and self-confidence, Mike had a chance to realize some of his career aspirations. After a long hard road, Mike is now

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[14] These were not included in Figure 1 because of space considerations

Director of the Oregon Consumer Technical Alliance (OCTA), the largest consumer/survivor run agency in Oregon. Having this respected title affords Mike even more “actual power” to help people who are currently struggling to find their way.

As shown in Figure 1, 69 percent of the participants reported social activism as a "recovery method." Participants such as Mike are now working to make the system better and to educate the public about mental health issues.

Carol Patterson spoke about her role as an activist:

> To me it is about truth, and ensuring that the public and the mental health system know the truth. And the truth is, you can't heal me without my cooperation, you cannot. There's no such thing as forced healing. We have to be active partners. That to me is what social action is about. It's sometimes about confronting this giant - it may be the drug companies, public opinion, the legislature - these huge powerful images, and confronting them with the truth. It also means that your voice has to be heard. You have to be loud sometimes. I think it's really important to be loud, and at the same time make sense and tell the truth.

Carol describes her worst time as when she just accepted her diagnosis and everything the doctors told her. Many of the other participants also felt that standing up for themselves, being "difficult" in essence, helped them break away and establish self-sufficiency. Kris Yates explains how this type of attitude helped her:

> I think the main thing that was most helpful to me was that I never really accepted the diagnosis. They diagnosed me, but I never thought I was mentally ill or that I had schizophrenia or had anything. I really rejected the drugs totally.

She felt that having this type of attitude might have prevented more hospitalizations. Kris went on to describe how she got involved in peer counseling, which helped her personal development. Along with being empowered, participants found that finding some type of support network was crucial to their recovery process.

Importance of Support

Figure 1 shows that 72 percent of the participants reported family and/or friends as instrumental in their recoveries. In fact, having a supportive family member or friend can sometimes mean the difference in getting out of the hospital, an important step on the road to recovery.

David Oaks, the 45-year-old Executive Director of Support Coalition International (SCI), remembers how he got out of McLean Hospital in Boston:

> I found out that even a few empowered peers supporting each other could make a huge difference in my life. During my last stay in McLean, Mental Patient Liberation Front (MPLF) activists helped me by complaining to the facility. A MPLF activist dictated over the phone to me the proper legal letter that I would need to try to get out. Through a Haldol haze I meticulously printed out the letter and filed it. I found out later that the authorities reacted by contacting my parents, asking them to either commit me, seek guardianship, or dissuade me from doing this. My mother told them, "If our David wants to try freedom, we support him."

Because David had the support of his parents and his MPLF friends, he was able to avoid additional time in the hospital.

Unfortunately, for people like Tony Lipinsky, who lack an active support network, their path to recovery can be a bit rockier. Tony explains what it can be like for people who lack support:

> One very important thing that I really want to focus on is that these experiences can vary dramatically, depending on whether or not you have an outside support system. If you have somebody fighting in the outside world for you, for example family, that's the most important thing, and some of these things may not happen. A lot of them are going to happen anyway, but at least you have somebody out there, a life preserver. In my case my parents had passed away, I had no further family, my wife had passed away. I had nobody out there whatsoever to fight for me and that's a case with a lot of consumers . . . You're totally powerless and that's the time when the person can turn on you the worst because they perceive you in two ways. One, you're a random factor who can go out and do anything. Two, without a support system, they pretty much can control your life. If they make a mistake, well who's going to worry? Heck, I could have died!

Luckily, after being homeless for a brief time, Tony was finally able to find some support at a consumer-run agency in Portland, Oregon.

Pat Risser describes the importance of finding peer support:

> My peers and friends in support groups did understand and they never tried to "treat" me. Instead, they gave me love, understanding, kindness and support. I built upon my experiences in the support groups and started to heal.

Pat, Jody, Tony, and many other participants felt that finding peer support was crucial in large part because those who went through similar experiences were able to *validate* their experiences. In the system, the participants were all told that they were "crazy" and many felt like their thoughts and feelings no longer mattered or counted. Thus, finding support and validation amongst their peers was integral to improving their well being.

Conclusion: Policy Implications

A common theme in the interviews was that people did not get "better" or "recover," until they took control of their own "treatment," whether it was meditation, exercise, peer support, or psychiatric drugs. This idea has powerful implications for policies such as Involuntary Outpatient Commitment (IOC) and the Program for Assertive Community Treatment (PACT), which both severely limit peoples' right to self-determination. It also suggests policies that encourage self-determination and support the use of holistic alternatives should be implemented and funded.

IOC and PACT

IOC comes in many forms and has been adopted in 37 states and the District of Columbia. The American Psychiatric Association (APA) defines IOC as *court-ordered outpatient treatment for patients who suffer from severe mental illness and who are unlikely to comply without the use of a court order* (GAO, 2000). Under IOC, a person is required by law to take prescribed medications and attend regular follow up appointments with mental health professionals.[15]

Partly because states were not enforcing IOC, the National Alliance for the Mentally Ill (NAMI) developed the Program for Assertive Community Treatment (PACT), which is active in 26 states (Oaks, 2000). PACT teams of 10 to 12 mental health professionals (directed by a licensed psychiatrist) provide round-the-clock, comprehensive services 24 hours per day, 365 days per year. Services include the supervised dispensation of psychiatric drugs, skill teaching, supportive therapy, group therapy, and supported employment.

Proponents of IOC argue that it reduces hospital recidivism and costs significantly less than inpatient hospitalization, while providing treatment in a less restrictive setting (Ridgely, 2001). In support of this view, a randomized study in North Carolina found that IOC, combined with intensive services, was associated with a significant decrease in hospital use (Swartz et al., 1999). Several other studies have also found that assertive community treatment is more cost-effective than hospitalization (GAO, 2000).

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[15] IOCs can be issued for patients who are either in the process of being discharged from a hospital or who are brought to court by somebody close to them (e.g., law enforcement officer, mental health professional, family member, or housemate). Common criteria include: (1) Person is mentally ill, (2) Person is in need of treatment to prevent further deterioration, (3) Person has history of "noncompliance," (4) Person is able to live safely in community with supervision, (5) Nature of illness makes person unable to make informed decision, (6) Person is danger to him/herself or others (Hiday & Scheid-Cook, 1987).

Opponents of IOC question the validity of these studies. For example, they note that the North Carolina study found that IOC was actually associated with an *increase* in hospitalizations during the first 6 months of the program (Bazelon Center, 2001). Studies of PACT and PACT-like programs showing reduced hospital use may be subject to administrative bias as well. For instance, the psychiatrist in charge of the program may be reluctant to re-hospitalize patients in order to make her program look more effective (Gomoroy, 2001). Also, because state psychiatric care is extremely costly (around $500 per day), almost any alternative would be cheaper (Neugoboren, 1999). In addition, these studies don't take into consideration the costs of medication's side effects, which many of the participants found to be severe. In fact, a major contributor to rising mental health care costs is costs associated with medications used to treat the side effects of other medications (Bazelon Center, 1999).

Mental Patients as a Target Group

Mental health policies such as IOC and PACT can be better understood using Schneider & Ingram's (1997) concept of socially constructed target groups. Their theory posits that citizens' opinions of themselves and the political world are partially shaped by their experiences with public policy. These experiences and reactions to policy, in turn, affect future social constructions and policy decisions. Policies directed at the participants of this study, or the "mentally ill," usually construct this population as dependents unable to care for themselves, or deviants who present a danger to society.

In the case of IOC, how this target group is constructed depends on the degree to which people with mental illness comply with the law. If outpatients refuse to comply with treatment, with the focus being on taking their prescribed medications, they can be forced to comply with a court order. As long as patients comply with the law, they are viewed as dependents. It is assumed that policy-makers and psychiatrists know what treatments are best for the “mentally ill,” who are unable to make decisions on their own. Political rhetoric presents the policy as beneficial for a group who can’t otherwise care for themselves.

However, a significant percentage of those viewed as mentally ill do not see IOC as a beneficial policy because they want to be able to determine their own course of treatment without being coerced. Those that don’t agree with the policy, or who refuse their medications are marginalized and treated as deviants.

A closer look at the political underpinnings of IOC reveals that rhetoric describing the mentally ill as dependents is just that, rhetoric. This rhetoric belies the true social intent of attempting to control a group that is negatively constructed as deviants. For example, recently the Attorney General of New York, Eliot Spitzer, pushed hard for IOC after the highly publicized incident where Andrew Goldstein, diagnosed with schizophrenia, pushed Kendra Webdale into the path of an oncoming subway, killing her. Goldstein was not taking medications at the time.

The media hype surrounding this event perpetuated the stereotype of the "violent mental patient," even though studies have suggested that mentally ill persons are no more likely to be violent than the average person (Wickens, 1998). In fact, New Yorkers refer to their IOC as Kendra’s Law, a constant reminder of its frightening origins. Because people with "mental illness" tend to migrate between categories of dependency and deviancy, politicians may resort to rhetoric while implementing policies such as IOC in an attempt to appease all constituents. Beneath the empty rhetoric is the popular belief that mental patients are dangerous and depend on their medication to control their behavior. The participants of this study, most of whom are not taking psychiatric drugs, attest to the fact that these generalizations are not grounded in fact.

The consumer/survivor movement and the groups associated with it receive little popular press in part because they counter prevailing scientific norms. Schneider & Ingram (1999) point out that people tend to trust science and its construction of knowledge. As discussed, the dominant paradigm in our society views mental illness as strictly a biological “brain disease” similar to cancer and diabetes, and treatable by medication. People in the movement who question this paradigm are marginalized further, and are called "radical" or even "militant." Licensed psychiatrists and doctors, such as Peter Breggin (author of *Toxic Psychiatry*) and Dan Fisher (director of the National Empowerment Center) who “defect” to the consumer/survivor side are either considered amateurish or highly radical. Thus, evidence supporting alternate explanations of mental illness focusing on situational/sociological factors and positive evaluations of alternative treatment strategies are discounted or ignored.

Mental health institutions have allied themselves with a powerful advantaged interest group, the pharmaceutical industry. Schneider & Ingram (1997) also warn that alliances such as these can lead to oversubscription of policies that benefit these groups. Drug companies form a powerful lobby. They are very successful at obtaining money for research into newer and “better” medications, as well as lobbying for legislation such as IOC that encourage adherence with the medical model. In this case, science itself is benefiting from policies that are supported by science. This can be a difficult cycle to break because the scientific community tends to close ranks when challenged by explanations that will ultimately hurt its interest.

This "marriage" between drug companies and the field of psychiatry has helped to create an image that "mentally ill" people prefer a label that relieves them of responsibility, but this not necessarily the case. Most of the participants in this study actively rejected psychiatric labels because they found them disempowering. In fact, when people labeled with mental illness do view themselves this way, as “sick,” it may be because science itself was integral in forming this passive attitude in the first place. Drug companies and the scientific research associated with it have much to gain from the mental illness label. If mentally ill people view themselves as passive recipients of care, they will take more medication, and these advantaged groups will find themselves better off. This perpetuates a cycle of social labeling that benefits pharmaceutical companies and scientific institutions in the name of reaching out to disenfranchised sufferers of "mental illness."

By definition, IOC limits clients’ rights to determine their own treatment strategies. In fact, coercion (if not outright force) is often used to “convince” patients under IOC to take their medication. Many of the participants in this study experienced this type of coercion while in the system, and being on an IOC can make it worse. In my interview with David Oaks, for example, he gave me the example of a PACT team that offered a client new furniture *if* he took his medication. In large part to due to its coercive nature and reliance on psychiatric drugs, the vast majority of consumer/survivor groups oppose IOC and ACT (NCD, 2000).

Toward Progressive Mental Health Policy

The study's participants have demonstrated that complete recovery from "severe mental illness" is possible. Most of the participants have returned to work, are "productive" citizens, and have found effective ways to maintain their sense of well being. Interestingly, most of the participants have accomplished this without the use of psychiatric drugs. In fact, all of the participants, even those currently taking medications, described the adverse effects of these drugs, as well as other "treatments," in detail. All of this suggests that the medical model may not be working as well as it could, and that policies that reflect a more holistic conception of "mental illness" should be supported. In fact, research has indicated that alternative therapies focusing on empowerment and recovery compare favorably to traditional approaches.

For example, in 1971 an alternative to psychiatric hospitalization called the "Soteria" house was systematically compared to traditional inpatient facilities. The Soteria house was totally voluntary (including medications), peer support and self-determination were encouraged, and the primary task of staff members was to put themselves in the client’s “shoes”: to understand the immediate circumstances and relevant background that led to the crisis. After two years, the clients of the original Soteria house were working at significantly higher occupation levels, were living more independently or with peers, and had fewer re-hospitalizations than those treated in traditional settings (Mosher, 1999). The vast majority of these individuals accomplished this without the use of medication. Since that time, several other programs have incorporated many of the same philosophies as the original Soteria house.

In terms of evaluation, the Soteria house and its "spin-offs" have fared quite well. Studies of Soteria-model alternatives generally find that they have as good or better outcomes than traditional programs at significantly less cost. A Soteria spin-off, the McAuliffe house, produced similar clinical results as psychiatric hospitals, at 40% less cost. In fact, a review of studies on alternatives found that 19 of 20 studies reported that alternative treatments were as, or more, effective than hospital care at 43% less cost (Mosher, 1999).

The consumer/survivor community endorses these types of programs because they support an individual's right to take responsibility for his/her course of treatment and recovery. Despite this endorsement and despite clinical success, Soteria-model programs have generated little political and financial support. Thus, there seems to be a gap between available evidence and clinical practice (Mosher, 1999). Often, these programs are funded as "pilot" projects, demonstrate initial success, and then are not re-funded (Mosher, 1999). For example, the original Soteria house lost its funding source after five years, even after demonstrating positive outcomes. On reason for this is programs that don't require the use of medication have a more difficult time getting past Institutional Review Boards (IRBs) that are firmly entrenched in the medical model (Mosher, 1999). However, although there are substantial barriers, some consumer/survivor advocates have found success. For example, consumer/survivor groups in California recently blocked impending IOC legislation and were able to pass a bill that stresses the use of voluntary services (Oaks, 2000).

The study's participants have demonstrated that there is no magic bullet that works for all people who experience severe emotional distress, altered states, or "mental illness." This suggests policies should be enacted that support and fund alternatives such as peer-run programs, acupuncture, massage therapy, and yoga. For instance, currently Medicaid and Medicare waivers do not cover peer-run programs, a policy that could be changed (NCD, 2000).

Supporting alternatives may also require stricter oversight of Managed Care Organizations (MCOs) and parity of insurance (NCD, 2000). Massachusetts and several other states are contracting with private MCOs that operate for-profit, capitated, closed-network systems. Thus, financial considerations are emphasized over clinical outcomes, which has led to a reliance on medication prescriptions and cutting therapy down to 15 minute per week medication maintenance sessions (NCD, 2000). As discussed, the study's participants reported that establishing a bond with their therapist was important, if not crucial to making strides in their recovery. Limiting both the time and content of therapy sessions makes it less likely that people will be able to find that "one good therapist" who really helps. Currently, states offer little or no oversight of MCOs (NCD, 2000). Perhaps states should install stricter evaluation procedures to ensure that MCOs are meeting not only the needs of providers, but of the people they serve as well.

Many alternative treatments, such as acupuncture, are now covered by insurance for physical illnesses. However, these same treatments are not covered for mental disabilities, even though many consumers/survivors, including those in this study, have found these alternatives to be healing. Establishing parity in insurance for those labeled with mental disabilities is another way to provide better access to alternative therapies.

Because those labeled with psychiatric disabilities are over-represented by the poor and the homeless, reforming social welfare policy could be an indirect way of assisting this population. Obviously, not having access to affordable housing, basic medical care, and meaningful work can make it more difficult to be mentally healthy. In fact, a recent University of Pennsylvania study found that providing supported-housing to a group of homeless individuals in New York city was cost-effective, reducing state psychiatric hospital costs by $8,260 and inpatient Medicaid costs by $3,787 for each supported-housing unit (Bernstein, 2001). Thus, providing housing was able to keep many of these people out of the hospital, improving their lives as well as saving taxpayer dollars.

As deinstitutionalization continues, providing affordable housing is also way to help integrate marginalized groups such as the "mentally ill" into local neighborhoods. Unfortunately, myths such as the "violent mental patient" make it less likely that communities will truly embrace this population with open arms. Hopefully, as states begin to implement their Olmstead plans (which require maximizing interaction between those and without disabilities), communities will find that many of these stereotypes are unfounded and will recognize their own capacity to care for people experiencing problems in living.

References

Banks, E. (1997). The social capital of self-help mutual aid groups. *Social Policy*, 28, 30-38.

Bazelon Center for Mental Health Law(1999). Medicaid Formulary Policies: Access to High-Cost Mental Health Medications. http://www.bazelon.org/formulary.html (April 30, 2001).

Bazelon Center for Mental Health Law (2001). Olmstead v. L.C. http://www.bazelon.org/adatitl2.html#L.C. (November 11, 2001).

Bazelon Center for Mental Health Law (2001). Studies of Outpatient Commitment are Misused. Revised March 16, 2001. http://www.bazelon.org/opcstud.html

BBC News (2000). Prozac 'may encourage suicide.' Health Section, Monday, May 22. http://news.bbc.co.uk/hi/english/health/newsid_758000/758763.stm (December 9,2001).

Bernstein, N. (2001). "Housing Mentally Ill People is Cost-Effective, Study Finds." *New York Times*, May 2, 2001.

Blanch, A. et al. (1995). "Identity Politics" close to home. *American Psychologist*, 50, 49-50.

Boodman, S. (1996). "Shock Therapy… It's Back." *The Washington Post*, Tuesday, September 24, pp. Z14.

Breggin, P. (1991). *Toxic Psychiatry*. New York: St. Martin's Press.

Breggin, P. & Cohen, D. (1999). *Your Drug May Be Your Problem*. New York: Perseus Publishing.

Cannon, L. et. al. (1991). Race and class bias in qualitative research on women. In M.M. Fonow and J.A. Cook, eds., *Beyond Methodology: Feminist Scholarship as Lived Research* (pp. 107-118). Bloomington: Indiana Press.

Caplan, P. (1995). *They Say You're Crazy: How the World's Most Powerful Psychiatrists Decide Who's Normal*. Reading, Massachusetts: Perseus Books.

Chamberlin, J. (1997). A working definition of empowerment. *Psychiatric Rehabilitation Journal*, 20, 43-46.

Chamberlin, J. (1990). The ex-patients' movement: Where we've been and where we are going. *The Journal of Mind and Behavior*, 11:323-336.

Dickey, B. (1997). The Cost and Outcomes of Community-Based Care of the Seriously Mentally Ill. *Health Services Research*, 32(5):599-614.

Fisher, D. & Ahern, L. (1999). Ensuring that people with psychiatric disabilities are the leaders of self-determination and consumer controlled initiatives. Prepared for the National Leadership Summit on Self-Determination and Consumer Direction and Control, Bethesda, MD, October 21-23, 1999.

Fisher, D. (1998). Recovery: the behavioral healthcare guideline of tomorrow. *Behavioral Healthcare Tomorrow*, June, 1998.

Frisch, D. & Sisson, L. (2001). Diagnosis for dividends. *MindFreedom Journal*, Issue #44, Summer 2001, pp. 18-19.

Frisman, L. & McGuire, T. (1989). The Economics of Long-Term Care for the Mentally Ill. *Journal of Social Issues*, 45(3):119-130.

General Accounting Office (GAO) (2000). Mental Health: Community-Based Care Increases for People with Serious Mental Illness. United States General Accounting Office Report to the Committee on Finance, U.S. Senate, December, 2000.

Ghaemi, S. (1997). Insight and psychiatric disorders: A review of the literature, with a focus on its clinical relevance for bipolar disorder. *Psychiatric Annals*, 27, 782-790.

Gomory, T. (2001). Programs of Assertive Community Treatment (PACT): A Critical Review. Florida State University School of Social Work. http://www.mindfreedom.org/mindfreedom/pact_b.shtml. (April 2, 2001).

Herbert, W. (1998). Troubled at work: the courts are skeptical about mental disability claims. *U.S. News and World Report*, 124: 62-64.

Herman, J. (1997). *Trauma and Recovery.* New York: BasicBooks.

Hiday, V. & Scheid-Cook, T. (1987). The North Carolina Experience with Outpatient Commitment: A Critical Appraisal. *International Journal of Law and Psychiatry*, 10:215-232.

Huskamp, H. (1999). Episodes of Mental Health and Substance Abuse Treatment Under a Managed Behavioral Health Care Carve-out. *Inquiry*, 36:147-161.

Kamis-Gould, E. et al. (1999). The Impact of Closing a State Psychiatric Hospital on the County Mental Health System and Its Clients. *Psychiatric Services*, 50(10):1297-1302.

Kessler, R. et al. (1998). A Methodology for Estimating the 12-Month Prevalence of Serious Mental Illness. In R.W. Manderscheid and M.J. Henderson, eds., *Mental Health, United States*, 1999, pp. 99-109. Rockville, Maryland: Center for Mental Health Services.

Lovejoy, M. (1982). Expectations and the recovery process. *Schizophrenia Bulletin*, 8, 605-609.

Mead, S. & Copeland, M. (2000). What recovery means to us: Consumers' perspectives. *Community Mental Health Journal*, 36, 315-328.

McKnight, J. (1995). *The Careless Society*. New York: Basic Books.

McLean, A. (1995). Empowerment and the psychiatric consumer/ex-patient movement in the United States: Contradictions, crisis and change. *Social Science & Medicine*, 40, 1053-1071.

Mondimore, F. (1999). *Bipolar disorder: A Guide for Patients and Families*. Baltimore and London: John Hopkins University Press.

Mosher, L. (1999). Soteria and Other Alternatives to Acute Psychiatric Hospitalization: A Personal and Professional Review. *The Journal of Nervous and Mental Disease*, 187:142-149.

Mowbray, C. & Freddolino, P. (1986). Consulting to implement nontraditional community programs for the long-term mentally disabled. *Administration in Mental Health*, 14, 122-134.

National Council on Disability (NCD) (2000). From Privileges to Rights: People Labeled with Psychiatric Disabilities Speak for Themselves. http://www.ncd.gov/newsroom/publications/privileges.html

National Empowerment Center (NEC) (1999). Consumer/Survivor History Project. http://www.power2u.org/how.html (December 4, 2001).

Neugeboren, J. (1999). *Transforming madness: New Lives for People Living with Mental Illness*. New York: William and Morrow Company, Inc.

Oaks, D. (2000). Talking Points: Why Forcing Psychiatric Drugs into Your Home is a Bad Idea. *Dendron*, 43:20-23.

Putnam, R. (2000). *Bowling Alone*. New York: Simon and Schuster.

Reidy, D. (1994). The mental health system as an agent of stigma. *Resources*: Workforce Issues in Mental Health Systems, 6, 3-10.

Ridgely, S. (2001). The Effectiveness of Involuntary Outpatient Treatment: Emperical Evidence and the Experience of Eight States. Santa Monica, CA, RAND, MR-1340-CSCR.

Rogers, E. et al. (1997). A consumer-constructed scale to measure empowerment among users of mental health services. *Psychiatric Services*, 48, 1042-1047.

Schneider, A. & Ingram, H. (1997). *Policy Design for Democracy*. University of Kansas Press.

Smith College URL (2001). http://www.smith.edu/nsh/dein.html (November 28, 2001).

Spaniol, L. (1999). Implications of recovering for mental health systems and programs. Prepared by Center for Psychiatric Rehabilitation at Boston University for APA Presentation, August, 1999.

Support Coalition International (SCI) URL (2001). News Release: A PACT worker breaks the silence, June 30, 2001. http://www.mindfreedom.org/mindfreedom/worker.shtml (December 15, 2001).

Swartz, M. et al. (1999). Can Involuntary Outpatient Commitment Reduce Hospital Recidivism?: Findings From a Randomized Trial With Severely Mentally Ill Individuals. *American Journal of Psychiatry*, 156(12):1968-1975.

Tardive Dyskinesia/Tardive Dystonia National Association (2001). A Beginner's Guide to Tardive Dyskinesia. Prepared for the 2001 National Association for Rights Protection and Advocacy (NARPA) Conference, November 1-4, Niagara Falls, NY.

The Schizophrenia Homepage (2001). Electroconvulsive Therapy. http://www.schizophrenia.com/family/ect1.html (December 10, 2001).

Van Hoorn, E. (1992). Changes? What changes? The views of the European patients' movement. *The International Journal of Social Psychiatry*, 38, 30-35.

Wickens, B. (1998). Unwell and untreated. *Maclean's*, 10:44-45.

Appendix A

Support Coalition International Fieldwork Datasheet

Created by Oryx Cohen, Director of the SCI Oral History Project

Tracking No.

Support Coaliton International: Fieldwork Datasheet

Name ____
last first middle title (nickname)

Male ____ Female ____ Birth Date ____________

Current Location (city, state) ____

Current Activities ____

____

____

____

Psychiatric label(s) in order given to you: ____

____

____

Mental Health System Experience (check all that apply):
Inpatient Outpatient Commitment Shock Psychiatric Drugs
Forced Treatment Coercive Treatment Rape Restraints Torture
Solitary Confinement Other ____

____

____

____

____

Psychiatric drugs (past and present) in order given to you: __________________________

____

____

Recovery Methods (check all that apply):

Self-Help   Peer Support   One-on-one Therapy   Group Therapy   Diet
Exercise   Psychiatric Drugs   Social Activism   Spirituality   Meditation
Literature   Consumer-run Groups   Art/Music   Family/Friends
Other____

____

____

____

Greatest Obstacle to Recovery: ______________________________________

____

____

This Information to be Kept Private Unless Otherwise Indicated

Address ____

City/State/zip ____

Check if okay to make address public

Phone number (____) ____________________ Check if okay to make phone public

E-mail ________________________ Check if okay to make e-mail public

Web page ________________________ Check if okay to make web page public

Ethnic Background __________________ Check if okay to make public

Religious Background __________________ Check if okay to make public

Educational Level __________________ Check if okay to make public

Marital Status __________________ Check if okay to make public

Number of Children __________________ Check if okay to make public

Annual Income __________________ Check if okay to make public

Appendix B

Support Coalition International Preview Questions

Created by Oryx Cohen, Director of the SCI Oral History Project

SUPPORT COALITION INTERNATIONAL
ORAL HISTORY PROJECT

PREVIEW QUESTIONS
(Please do not answer now)

Main Questions

1. **A. Can you describe the process you went through in recovering from periods of intense emotional distress?**

   B. Can you describe how you overcame human rights violations in the mental health system?

Specific Questions

EMOTIONAL DISTRESS

2. Looking back, if you became emotionally distressed, what do you think caused it to happen?
    a. Do you think it was inevitable?
    b. Does it depend on the circumstances?
    c. Did you feel that you have support during these times?
    d. Describe your most intense periods of emotional distress.

PSYCHIATRIC INSTITUTIONALIZATION

3. What happened when you were inside a psychiatric institution?
    a. How many times were you in such institutions?
    b. What was your longest stay?
    c. Were these stays helpful/unhelpful? Why?
    d. What hospitals did you stay at? Who were your doctors?
    e. Did you receive electroshock? Solitary confinement? Forced drugging? Restraints? Other abuses?
    f. When is the last time you were in contact with the psychiatric system?
    g. How did you get free of the mental health system?
    h. How did you win your human rights?

SOCIAL ACTIVISM

4. How has social activism affected your recovery and/or personal development?
    1. Are you currently working in the mental health system?
    2. Have you ever worked in the mental health system?
    3. Are you active in human rights in psychiatry campaigns?

DISCRIMINATION

5. How well do you think you fit in with mainstream society?
    a. Have you experienced discrimination?
    b. Have you experienced stigma?
    c. Are you “out of the box” or open with your psychiatric history?
    d. Do feel more comfortable sharing your history with certain people? Why?

PSYCHIATRISTS

6. Describe your interactions with psychiatrists, counselors and other mental health practitioners.
    a. Were any of them particularly helpful or unhelpful? Why?
    b. Did you trust the mental health system when you first received services (either voluntarily or involuntarily)?
    c. Do you trust the mental health system now?

PSYCHIATRIC DRUGS

7. Describe your experience with prescribed psychiatric drugs.
    a. Are you currently taking any of these drugs?
    b. Which of these drugs have been prescribed to you in the past?
    c. Did (Do) they help?
    d. What have been the affects of these drugs?
    e. Have you ever been coerced, misled, or pressured to take these drugs?
    f. If not currently on psychiatric drugs, how did you get off of them?

GROUP THERAPY

8. Describe your group therapy experiences.
    a. Did these sessions help? Why or why not?

SOCIAL SUPPORT

9. Describe the involvement of your family and friends during these times.
    a. Were any of them particularly helpful or unhelpful? Why?

CONSUMER-RUN GROUPS

10. Describe your experience with consumer-run groups.
    a. Did they help? Why or why not?

PEER SUPPORT/SELF-HELP

11. Describe your experience with peer support and/or self-help.
    a. Did they help? Why are why not?

OTHER STRATEGIES

12. Did you use other strategies to overcome emotional distress?
    a. Did you regulate/change your diet? Explain.
    b. Was finding spirituality important? Explain.
    c. Were any books, magazines, or videos especially helpful? Explain.
    d. Was art or music a major factor? Explain.

CURRENT ACTIVITIES

13. What you are currently doing?
    a. Are you working? If yes, what is your occupation?
    b. Do you feel like you are doing something important?
    c. Do you volunteer?
    d. Do you have any hobbies?

GENERAL RECOVERY QUESTIONS

14. What was most important in your recovery process?

15. What was the greatest challenge or obstacle that you had to face?

16. How did you know you were making progress?

17. How have your aspirations or goals changed since you first encountered the mental health system?

18. What does "recovery" mean to you?

19. Do you think we need to redefine mental illness? If yes, how should it be redefined?

20. What is your vision of the ideal mental health system?

Appendix C

Support Coalition International Informed Consent

Created by Oryx Cohen, Director of the SCI Oral History Project

SUPPORT COALITION INTERNATIONAL
ORAL HISTORY PROJECT

CONSENT FORM

I, ________________________ agree to participate in the Support Coalition International (SCI) Oral History Project, which is being conducted by SCI staff and volunteers.

I understand that the purpose of this project is to gather stories from people labeled with psychiatric disabilities who have been through the psychiatric system in the past, or are currently in that system.

I understand that I will only reveal what I feel comfortable revealing during the course of the interview. I can end the interview at any time. I understand that the focus of the conversation will be on my experience with the psychiatric system and my recovery process.

I understand that the interview may be recorded and/or videotaped. I understand that the recording and/or video footage may be used for a web page, public documentary, or for historical purposes. I understand that at any time during the conversation I may notify the interviewer to immediately stop the recording and/or video.

I have read and understood the above information and I agree to participate.

____

____

Signature of Participant Signature of Interviewer

__________ __________

Date Date

Appendix D

Support Coalition International Release Form

Created by Oryx Cohen, Director of the SCI Oral History Project

SUPPORT COALITION INTERNATIONAL
ORAL HISTORY PROJECT

RELEASE AGREEMENT

By signing this form below, I give my permission for the Support Coalition International (SCI) Oral History Project to:

- Use my interview--including any audiotapes, video, photographs, or written information--for historical study and artistic presentation, including web page, video, and print publication.

- Deposit these materials in publicly accessible archives where they can be catalogued and preserved.

By signing below, I agree that SCI may copyright the material it produces in exchange for the project's work in preserving this information and making it available internationally.

I agree to the uses of these materials described above except for any restrictions listed below:

Participant:

Signature____

Printed Name____________________________ Date ____________

Interviewer:

Signature___________________________ Date ____________

Restrictions - You may place restrictions on both the interview process and the contents obtained from the interview; however, consideration must be made as to how these restrictions will affect the goals and objectives of the SCI Oral History Project. The following are some of the more common restrictions. Please check those that apply. If you have restrictions that are not listed below, please list them on the back of this form:

☐ My interview will not be videotaped.
☐ My photo will not be taken, nor can any photos of me be used in the project.
☐ My interview will not be tape recorded.
☐ My name will not be mentioned or otherwise associated with any of the materials or information obtained in the interview.
☐ The information and other materials obtained from me by The SCI Oral History Project will not be used until _______ (date)

Appendix E

Support Coalition International Interview Protocol

Created by Oryx Cohen, Director of the SCI Oral History Project

SCI ORAL HISTORY PROJECT

INTERVIEW PROTOCOL

Step One: Interviewer describes SCI Oral History Project and its purpose
Step Two: Interviewer provides preview questions
Step Three: Interviewer fills out fieldwork data sheet (FDS) with interviewee
Step Four: Interviewer schedules the interview time and place
Step Five: Interviewee reads and signs consent and release forms
Step Six: The interview itself (see below)

Main Questions

2. **A. Can you describe the process you went through in recovering from periods of intense emotional distress?**

B. Can you describe how you overcame human rights violations in the mental health system?

Potential Probing Questions (depending on FDS responses)

EMOTIONAL DISTRESS

4. Looking back, if you became emotionally distressed, what do you think caused it to happen.
    a. Do you think it was inevitable?
    b. Does it depend on the circumstances?
    c. Did you feel that you have support during these times?
    d. Describe your most intense periods of emotional distress.

PSYCHIATRIC INSTITUTIONALIZATION

5. If you are comfortable, can you tell me more about what happened when you were inside a psychiatric institution?
    a. How many times were you in such institutions?
    b. What was your longest stay?
    c. Were these stays helpful/unhelpful? Why?
    d. What hospitals did you stay at? Who were your doctors?
    e. Did you receive electroshock? Solitary confinement? Forced drugging? Restraints? Other abuses?
    f. When is the last time you were in contact with the psychiatric system?
    g. How did you get free of the mental health system?
    h. How did you win your human rights?

SOCIAL ACTIVISM

4. How has social activism affected your recovery and/or personal development?
    1. Are you currently working in the mental health system?
    2. Have you ever worked in the mental health system?
    3. Are you active in human rights in psychiatry campaigns?

DISCRIMINATION

11. How well do you think you fit in with mainstream society?
    a. Have you experienced discrimination?
    b. Have you experienced stigma?
    c. Are you "out of the box" or open with your psychiatric history?
    d. Do feel more comfortable sharing your history with certain people? Why?

PSYCHIATRISTS

12. Can you tell me more about your interactions with psychiatrists, counselors and other mental health practitioners?
    a. Were any of them particularly helpful or unhelpful? Why?
    b. Did you trust the mental health system when you first received services (either voluntarily or involuntarily)?
    c. Do you trust the mental health system now?

PSYCHIATRIC DRUGS

13. Can you tell me more about your experience with prescribed psychiatric drugs?
    a. Are you currently taking any of these drugs?
    b. Which of these drugs have been prescribed to you in the past?
    c. Did (Do) they help?
    d. What have been the affects of these drugs?
    e. Have you ever been coerced, misled, or pressured to take these drugs?
    f. If not currently on psychiatric drugs, how did you get off of them?

GROUP THERAPY

14. Can you tell me more about your group therapy experiences?
    a. Did these sessions help? Why or why not?

SOCIAL SUPPORT

15. Can you tell me more about the involvement of family and friends during these times?
    a. Were any of them particularly helpful or unhelpful? Why?

CONSUMER-RUN GROUPS

16. Can you tell me more about your experience with consumer-run groups?

    a. Did they help? Why or why not?

PEER SUPPORT/SELF-HELP

11. Can you tell me more about your experience with peer support or self-help?
    a. Did they help? Why are why not?

OTHER STRATEGIES

12. Did you use other strategies to overcome emotional distress?
    e. Did you regulate/change your diet? Explain.
    f. Was finding spirituality important? Explain.
    g. Were any books, magazines, or videos especially helpful? Explain.
    h. Was art or music a major factor? Explain.

CURRENT ACTIVITIES

13. Can you tell me more about what you are currently doing?
    a. Are you working? If yes, what is your occupation?
    b. Do you feel like you are doing something important?
    c. Do you volunteer?
    d. Do you have any hobbies?

GENERAL RECOVERY QUESTIONS

20. What was most important in your recovery process?

21. What was the greatest challenge or obstacle that you had to face?

22. How did you know you were making progress?

23. How have your aspirations or goals changed since you first encountered the mental health system?

24. What does "recovery" mean to you?

25. Do you think we need to redefine mental illness? If yes, how should it be redefined?

20. What is your vision of the ideal mental health system?

Appendix F

Support Coalition International E-mail Survey

Created by Oryx Cohen, Director of the SCI Oral History Project

SUPPORT COALITION INTERNATIONAL
Oral History Project

The Support Coalition International (SCI) Oral History Project is designed to collect, preserve, and publish several stories of recovery, self-determination, and survival from the perspective of those who have experienced the mental health system first hand. The project involves interviewing several people labeled with mental disabilities who have struggled through difficult emotional times and an often abusive and patronizing psychiatric system, yet they survived, and even thrive. Surveys will be mailed or e-mailed to those people who can't be reached in person.

There are plenty of stories circulating about people labeled with mental disabilities who have "improved" or even "recovered," as a result of a strict diet of medication and perhaps a little therapy. Less is heard from the growing population of people who have experienced human rights violations in the psychiatric system, and who have fought through extremely difficult times, survived and are now functioning well, possibly even better than ever. Much can be learned from these people about the nature of survival, recovery, and well-being.

The following survey contains a wide range of questions regarding past experiences both within and outside of the mental health system. By qualitatively analyzing information from the interviews and surveys, we will be able to learn from those who have been through the system and survived. In the process, concepts such as survival, psychiatric abuse, self-determination, well-being vs. illness, and recovery should become more clear—and the experiences behind these concepts will be given a voice.

In the end, the project will take on two presentation forms. One form will involve a compilation of people's stories (with consent) as oral histories, or testaments to these very real experiences. These oral histories will be saved to CD Rom, displayed on the SCI home page, and used as a feature for *Mind Freedom* journal. These stories will allow people who have been through the psychiatric system to paint their own history, a history that often counteracts the medical model's story of progress and invention, known as the "master narrative." Reading and listening to stories of survival should also serve as sources of inspiration for people who find themselves in similarly difficult and traumatic situations.

The other form will involve qualitative research and the production of an academic paper for publication. Publishing in scholarly journals can help to legitimize a movement or a way of thinking and can be used as evidence in various policy and advocacy campaigns.

Survey Disclaimer

On the following survey, please feel free to fill out as much or as little as you feel comfortable. **The survey is lengthy: if a question does not apply to you, you can leave it blank.** If you need extra space, you can write on the back or attach extra sheets. In fact, if you prefer to share your story in free form, you are encouraged to include a longer version of your story in your own words. **Including photograph(s) of yourself to post on our web page would be ideal.** You are also encouraged to include any poetry or other artwork that expresses who you are and the transformations you have made.

Please return this form within one week of receipt, or processing of your materials may be delayed.

Most of you probably consider yourselves "psychiatric survivors" or "consumers." Many value-laden terms are thrown around in the dominant "mental health" culture including such terms as "mental illness," "hospitalization," and "medications." This survey attempts to use neutral terminology. Unfortunately, it is not possible to gear each survey toward individual preferences, though this would be ideal.

Before submitting your survey, please read carefully and sign the enclosed informed consent form. One of the major purposes of the SCI Oral History Project is to publish stories of survival, recovery, and self-determination. **Thus, unless otherwise indicated, the information you provide us will potentially be made public in the near future.** However, due to limited resources and the nature of the project, not all of the information we collect will be published. In most cases, excerpts from your survey or other submitted materials will be used, and the rest of the information you provide us will be archived.

ORAL HISTORY SURVEY

Oral History Information in Brief

Name:
Gender:
Birth Date:
Current Location (city, state):
Current Activities:
Psychiatric label(s) in order given to you:
Mental Health System Experience (check all that apply):
__ Inpatient
__ Outpatient
__ Commitment
__ Shock
__ Psychiatric Drugs
__ Forced Treatment
__ Coercive Treatment
__ Rape
__ Restraints
__ Torture/Abuse
__ Solitary Confinement
__ Other (explain):
Psychiatric drugs (past and present) in order given to you:
Recovery Methods (check all that apply):
__ Self-Help
__ Peer Support
__ One-on-one Therapy
__ Group Therapy
__ Diet
__ Exercise
__ Psychiatric Drugs

__ Social Activism
__ Spirituality
__ Meditation
__ Literature
__ Consumer-run Groups
__ Art/Music
__ Family/Friends
__ Other (explain):

Greatest Obstacle to Recovery:

This Information to be Kept Private Unless You Indicate Otherwise

Contact Information

Address:

City/State/Zip:

__ Okay to make address public

Phone number:

__ Okay to make phone public

Fax:

__ Okay to make fax public

E-mail:

__ Okay to make e-mail public

Web page:

__ Okay to make web page public

Ethnic Background:

Religious Background :

Educational Level:

Marital Status:

Number of Children:

Annual Income:

SURVEY QUESTIONS

EXPERIENCE IN THE PSYCHIATRIC SYSTEM

1. Have you ever been given a psychiatric label (e.g., schizophrenia, bipolar, etc.)?

    1a. Who gave you your label(s)?

    1b. Describe how you felt when you were labeled with a psychiatric disorder.

2. When were you last in a psychiatric institution (month/year)?

If you've never been in an institution, please go to the Emotional Distress section.

3. How many times in total have you been in a psychiatric institution, either voluntarily or involuntarily?

    3a. How many days/weeks/months/years in total have you been in a psychiatric institution?

    3b. How many times did you admit yourself "voluntarily" to these institutions?

    3c. How many times were you admitted involuntarily to these institutions?

    3d. What was the best part of being in a psychiatric institution?

    3e. What was the worst part of being in a psychiatric institution?

3f. In the psychiatric institution, were you ever:

Forcibly drugged? If yes, how many times? With what drug? Describe.

Forcibly restrained? If yes, how many times? For how long? What type of Restraint? Describe.

Forcibly electroshocked? If yes, how many times? What were the reasons given for it? How did it affect you in the short term? How did it affect you in the long term?

Placed in isolation? If yes, how many times? What were the reasons given for it? How did it feel? Describe.

Raped? If yes, how many times? Who raped you?

Abused physically? If yes, how many times? Who abused you? Describe.

Abused mentally? If yes, how many times? Who abused you? Describe.

Subjected to other abuses? Describe.

4. If you feel your rights were violated, how did you win your human rights? Did you win your rights as an individual? Did you win your rights as part of a group?

OUTPATIENT MENTAL HEALTH SERVICES

1. Are you currently receiving mental health services as an outpatient? If yes, what services are you receiving?

2. If not currently receiving mental health services, how did you get free of the mental health system?

3. Did you trust the mental health system when you first received services? Why or why not?

4. Do you trust the mental health system now? Why or why not?

PSYCHIATRIC DRUGS

Currently Taking Psychiatric Drugs

1. If you are currently taking prescribed psychiatric drugs, please list those drugs here:

Please list any psychiatric drugs you took previously here (in the order they were prescribed to you):

2. What have been the effects of these drugs, both positive and negative?

3. Were you ever misled about the effects of these drugs? Explain.

4. Were you ever coerced to take these drugs? Explain.

Not Currently Taking Psychiatric Drugs

5. If you are not currently taking psychiatric drugs, when were you last taking these drugs (month/year)?

Please list any psychiatric drugs you took previously here (in the order they were prescribed to you):

____

____

6. What were the effects of these drugs, both positive and negative?

7. Were you ever misled about the effects of these drugs? Explain.

8. Were you ever coerced to take these drugs? Explain.

9. How did you get off of psychiatric drugs?

EMOTIONAL DISTRESS

1. Looking back, if you experienced emotional distress, what do you think caused it?

2. Do you think severe emotional distress is/was inevitable? Why or why not?

3. Did you feel that you had support during these times in the past?

4. Do you feel like you have support now?

5. Describe your most intense periods of emotional distress.

EXPERIENCE WITH DISCRIMINATION/STIGMA

1. Have you experienced discrimination based on psychiatric labeling? If yes, please describe.

2. Have you experienced stigma based on psychiatric labeling? If yes, please describe.

3. Are you "out of the box" or open with your psychiatric history? If yes, describe the difficulties of "coming out."

4. Do you feel more comfortable sharing your mental health history with certain people? Why?

5. How well do you fit in with mainstream society? Explain.

RECOVERY

1. How has social activism (e.g., organizing, protesting, etc.) affected your recovery process and/or personal development?

2. How has literature, art, and/or music affected your recovery process? Were any books, videos, musical expressions or other art forms especially helpful or unhelpful? Why?

3. How have one-on-one interactions with psychiatrists, counselors, and other mental health professionals affected your recovery process? Were any of them particularly helpful or unhelpful? Why?

4. How have group therapy experiences affected your recovery process? Were they helpful? Unhelpful? Why?

5. How have your friends and family affected your recovery process? Have they been helpful? Unhelpful? Why?

6. How have consumer-run groups affected your recovery process? Were they helpful? Unhelpful? Why?

7. How has peer support and/or self-help affected your recovery process? Was it helpful? Unhelpful? Why?

8. Did you use other strategies to recover (e.g., regulating your diet, sleep, exercise, meditation, spirituality)? Were they helpful? Unhelpful? Why?

9. What was the single most important factor in your recovery process?

10. What was the greatest challenge or obstacle that you had to face in your recovery process?

11. How did you know you were making progress in recovering?

12. How have your goals and expectations changed since you first encountered the psychiatric system?

14. What does "recovery" mean to you?

VISIONS OF THE FUTURE

1. Do you think we need to redefine mental illness? If yes, how should it be redefined?

2. What is your vision of the ideal mental health system?

CURRENT ACTIVITIES

1. What are you currently doing?

    1a. Do you work? If yes, what do you do? If retired or not currently working, what kind of work did you do in the past?

    1b. Is your job rewarding? Why or why not?

    1c. Do you volunteer? If yes, what do you do and what do you get out of it?

1d. Do you have any hobbies? If yes, what are they and what do you get out of them?

The following information will be used for an academic study designed to gather evidence about the recovery process from the psychiatric survivor's perspective. Your answers to the following questions will remain completely anonymous and confidential.

1. Please rate the degree to which you agree or disagree with the following statements on a scale from 1 (agree strongly) to 5 (disagree strongly):

__ I have friends I can count on.

__ I am mentally ill.

__ I feel I make a positive impact on people.

__ I feel confident to make decisions on strategies to improve my “mental” health.

__ It helps to talk to people who have had similar experiences in the mental health system.

__ Overall, being in a psychiatric institution was a positive experience.

__ Taking psychiatric drugs works for me.

__ A spiritual discovery really helped to give me peace of mind.

__ I’m in control of my life.

__ I’m better off without psychiatric drugs.

__ My family supported me throughout my recovery process.

__ A mental health professional was instrumental in my recovery process.

__ I’m afraid of losing control

__ A book helped to turn things around for me.

__ I don't believe mental illness exists

__ Being in the hospital did me more harm than good.

__ I have a challenging job.

__ I feel as though I’ve made a complete recovery.

__ Recovering from psychiatric abuse was more difficult than recovering from other emotionally distressing events in my life.

__ Regulating my diet helped me through some rocky times.

__ I tend to use exercise as a way to alleviate stress during difficult times.

2. Please rank the following items in order of importance (1-8 or 1-9 if “Other” is filled in) to your recovery process from emotional distress and/or psychiatric abuse:

__ Social Support (friends, family, significant others)
__ Individual strategies (e.g., meditation, diet, exercise, regulating sleep)
__ Prescribed psychiatric drugs
__ Group counseling (other than self-help groups)
__ Peer Support/Self-help groups (e.g., run by consumers/survivors)
__ One-on-one professional counseling from a psychiatrist or licensed psychologist
__ Becoming part of a movement for social change
__ Spiritual discovery
__ Other (explain):