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MENTAL HEALTH CONSUMERISM REVEALED:
TOWARD A THEORY OF SOCIAL VULNERABILITY STATES

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MARION L. McCOY

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MENTAL HEALTH CONSUMERISM REVEALED:
TOWARD A THEORY OF SOCIAL VULNERABILITY STATES
Volume I

By

Marion L. McCoy

A DISSERTATION

Submitted to
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1989

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ABSTRACT

MENTAL HEALTH CONSUMERISM REVEALED: TOWARD A THEORY OF SOCIAL VULNERABILITY STATES

By

Marion L. McCoy

This research analyzes activities in one mental health alternative service organization operated by and for people labeled "chronically mentally ill." Participants' provision of effective support services to peers is examined within the context of a larger social problem, ineffective mental health care for people labeled "chronically mentally ill." My objective in this project was to ascertain the nature of mental health consumerism for people involved with this organization.

Documentary, in-depth interview, and field methods were used to collect data. Qualitative analyses were used to: construct a case study of the organization; profile participants' mental health treatment and organizational experiences; and identify suggestions for reforming the mental health system. Theoretical analyses relate findings to operations of the political economy and current mental health system practices.

Data analyses, informed by grounded theory methodology, reveal that the common element in experiences of mental health consumers is a concept I describe as a social vulnerability state. This refers to a disturbance in self or social identity that creates a need for a meaningful definition of situation from others (e.g., peers or professionals). The definition of the situation is a social construction of reality, anchored in

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structural relations. It is affected by personal biography and social position of "definer(s)" <u>and</u> persons seeking definition.

Analyses reveal that substantial investment in the work of the organization allows some consumers to realize a situated empowerment and a changed sense of self. Two components of organizational activity emerge as features allowing changed self-definitions and/or the resolution of felt social vulnerability. One is the transformation of the organization into a supportive community for peers in the mental health system. The second is realized within the community: in peer-to-peer interactions, consumers offer each other redefinitions of self or situation that allow them to alter insidious messages about self received in traditional mental health treatments (e.g., "chronically mentally ill"). Mental health consumers' embrace of new definitions is affected by their acceptance of the organization as a community; their level of involvement within the community; and the length of time participants formerly defined themselves as "mentally ill" persons.

Dedicated to the memory of my brother
Peter Gwin McCoy
whose excitement for learning and discovery
imbued our time together
and lights the path I travel still

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I wish to thank the Department of Sociology at Michigan State University for its generous financial support. The opportunity to acquire teaching and research acumen afforded by assistantships was no less important than the offer of financial assistance. Graduate fellowship awards also allowed me freedom to pursue my research interests, on and off-campus.

I especially wish to thank members of my guidance committee: Barrie Thorne, my first chairperson, whose early affirmation of this project's potential buoyed my spirits to its conclusion; Marilyn Aronoff, the chairperson who saw me through to the end, offered a welcome and kindred understanding of qualitative research processes and significant suggestions for final refinements; Bill Faunce, a trusted and respected intellectual guide who helped me clarify the focus of the final text; and Rita Gallin, whose discerning commentary on my first draft also helped me sharpen its final form. Don Olmsted, Chris Vanderpool, and Tom Reischl (the Dean's Representative) raised issues at my oral defense which were insightful and stimulating. I thank them all for their careful and thoughtful reading of the draft.

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I am also indebted to George and Judy McCoy, my parents, for their financial assistance during graduate school. Their subsidies during the final writing stages allowed me unfettered time and energy needed to complete the project. I am also grateful for their attention in my early years to issues of social inequality and the importance of social activism that made such an indelible impression on me. My brother, Robert McCoy, has also been an unceasing source of support.

I also wish to acknowledge the important camaraderie of fellow students and the intellectual growth stimulated by the dissertation support group (the "DSG") community I joined. Bradley Fisher was a good friend, important study-mate, and significant support during course work years; and Ginger Macheski, Delores Wunder, Cindy Negrey, Mary Roberson, Ginny Powell, and Ruth Harris were members of the "DSG" most active during my time with them. When all but one of these supporters left town for new jobs, I learned community can also be maintained over distance. I am grateful that Cindy Negrey carefully read and edited early chapters, and am indebted to Ginny Powell and Ruth Harris for their astute comments on all of them. But I credit Ruth Harris' devotion to our weekly, 2-person "DSG," as my critical support; her friendship and sustenance made it possible for me to finish the task.

Finally, I wish to thank the people of the "Alternatives By Consumers" organization, who must remain nameless here, for their moral support, their support for this study, their candor during interviews, and their devotion to "gentle justice" advocacy. Their work inspires hope for change.

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CHAPTER 1

INTRODUCTION

"Jane:" Profile of a Mental Health Consumer

"Jane's" story, which unfolds below, is drawn from data collected through in-depth interviews for this research project. She exemplifies the experience of many mental health consumers in the 1980s. The details of her profile foreshadow significant findings from this project.

> *Jane is a mental health consumer. She has been hospitalized for emotional difficulties several times in the past ten years. On her first admission, she was told her diagnosis was "major depression." A month later, when she was readmitted, her diagnosis was changed to "borderline schizophrenia." Two years and several hospitalizations later, her hospital record reflects another change in diagnosis, this time to "manic-depression." She was never quite sure why her diagnosis changed, but friends from the hospital told her it was important to have the "right" diagnosis. She hopes she has the "right" one now.*[1]
>
> *During each hospitalization, Jane was prescribed psychiatric medications. At first, she received a tranquilizer described to her as an "anti-depressant." When she was readmitted the next month, a different doctor gave her major tranquilizers, called "anti-psychotic medications." When her diagnosis changed to "manic-depression," her new doctor prescribed additional "anti-manic medications," and recommended that she continue taking both drugs. With continued use, Jane could learn to "manage her illness" and avoid inpatient care.*

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[1] Many consumers believe effective treatment depends on inclusion in their "correct" diagnostic group.

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Although she was rehospitalized after a homeless friend she knew from the hospital died, she continues to take her "meds," and believes what the doctor in the hospital said about them. Her outpatient treatment at the local Community Mental Health Center, with a different doctor, includes continued administration of both drugs.

Shortly after her first discharge and return to work, Jane noticed that her thinking was affected by the "anti-depressant." She felt "foggy" most of the time, and her work suffered (her boss pointed this out to her). She used her allotted "sick days" and "vacation days" to cover the time missed when she was readmitted a month later, but when she returned to work on the "anti-psychotic medication," it affected her vision, coordination, and slowed her typing speed. She also seemed increasingly aloof and afraid of her co-workers. Her boss noticed these things and justified firing her on the grounds that Jane could no longer adequately perform her job duties as receptionist/typist.

Jane's mother and step-father, and sometimes her brothers or sisters, had been sending her a little extra money each month. They knew the high unemployment rate in the area affected possibilities of her getting a better job anytime soon. Jane was surprised, but grateful for their help. When she left home after high school to escape her mother's alcoholic rages, contacts with family had been few and far between. After the second hospitalization, though, neither parents nor siblings sent her money. They told her they "wouldn't support her sick game playing." She hadn't talked to anyone in her family for years, but she did get a yearly Christmas card from one of her sisters.

After her second hospitalization, Jane didn't want to go back into the hospital when she was having coping difficulties, but her landlord committed her because her "behaviors" (pacing the floor during the night, putting "strange" drawings on her door) bothered the other tenants. Without the steady income from her job, and no financial help forthcoming from her family, Jane fell behind in rent payments, fueling the landlord's move to commit her. He evicted her after she was in the hospital.

Without housing or income, Jane traveled the circuit of temporary shelters (most of her friends disappeared with her job). Mounting stress resulted in another hospitalization. During it, an outside consumer-advocacy group made a presentation to the inpatients attending "day treatment." The group was called ABC (Alternatives By Consumers [a pseudonym]), and the Director of the organization was an expatient who also had received a diagnosis of "borderline schizophrenia" when he was hospitalized. Jane listened with rapt attention as he told his story of lonely struggle to regain his sense of self-worth following his hospital experiences. He said beginning the ABC organization and working with consumers allowed him to know

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who he "really was." Expatients, called "consumers" by ABC members, had together formed this organization to advocate for the rights of consumers in hospitals and community settings. When he described how the consumers at the "ABC Center" helped each other, he said people thought of ABC as their "family."

When Jane spoke to him afterwards, he gave her information on applying for disability benefits, securing residential after-care housing, and how to contact ABC during and after her hospital stay when she felt the need for support or help with community-living problems. She even spoke to him about the possibilities of volunteering at ABC and improving her job skills as she regained her self-confidence. Afterwards, Jane felt the stirrings of long-denied hope for a different future.

Jane's case is constructed from data presented by mental health consumers affiliated with the consumer-developed organization, Alternatives By Consumers (ABC), where this research project was based. The vagaries of her situation (e.g., rejection by family, loss of housing and job) and mental health care career (i.e., numerous changes in diagnoses, multiple prescriptions for psychiatric medications, frequent change in doctors) are common to many consumers at ABC. Jane, like most consumers of mental health care, learns from her treatment in the care system that her coping problems are signs of "chronic mental illness," probably caused by genetic factors which can be managed with medications. She is told, and comes to believe, that her coping problems are "private troubles." She feels better when she helps out at ABC, and makes some friends there, but she thinks that happens because they are "all in the same boat;" simply suffering from "private troubles" like hers.

The logic Jane uses to understand her situation, including her unquestioned acceptance of what her doctor said was wrong with her and how the condition could be managed, reflect

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flects a pervasive social understanding of "mental illness" and "mental patient" careers. However, the exploration of contemporary mental health consumerism undertaken in this project reveals that what appear as "private troubles" are verifiably public issues relating to the mental health care industry in the United States.

Overview of the Problem

One of the most persistent social problems[a] in the United States has been provision of mental health treatments and programs that allow recovery for people labeled "mentally ill." This is especially true for people who have been labeled "chronically mentally ill," a characteristic designation for most consumers using or operating the Alternatives By Consumers (ABC)[1] organization.

In the introduction to the Diagnostic Statistical Manual of Mental Disorders III (DSM III) used and developed by the American Psychiatric Association (1980), the definition of mental disorder (a synonym for "mental illness" used most frequently by practitioners) is:

> a clinically significant behavioral or psychological syndrome or pattern that occurs in an individual and that is typically associated with either a painful symptom (distress) or impairment in one or more areas of functioning (disability). In addition, there is an inference that there is a behavioral, psychological, or biological dys-

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[1] The name of this organization, and all names of people involved with it, have been changed to safeguard their anonymity. Persons who know of this unique organization or its principle actors may recognize the identities of some people despite attempts to disguise them. Their integrity and discretion in protecting others' privacy are solicited.

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> function, and that the disturbance is not only in the relationship between the individual and society (DSM-III 1980, 6).

The appellation of "chronic mental illness" presents different conceptual problems. Goldman (1984, 16) suggests that it has been "difficult to define operationally."

> It stigmatizes individuals with connotations of hopelessness and inevitable deterioration, and it obscures the heterogeneity of the population, grouping together a diversity of individuals under a single pessimistic rubric which some fear may become a self-fulfilling prophecy. *In spite of these limitations, we continue to use the term because of its widespread acceptance.* (Emphasis added.)

In general, the term is used to indicate that the emotional difficulties experienced by affected persons are enduring; there are periods with little or no distress that may last weeks or months, followed by periods when the original problems reappear. Some diagnostic categories in the DSM III are considered chronic if symptoms persist for more than six months (e.g., schizophrenia) while others are judged to be chronic only after one or two years duration.

In this project, I explore several dimensions of problems relating to treatment for people labeled "chronically mentally ill," focusing on an emerging trend in mental health care exemplified by the development of the ABC organization: provision of mental health support and advocacy services to consumers by (former and current) consumers. Contemporary practices in the mental health care system both facilitate the emergence of this trend and make it a necessary adjunct to traditional care.

Since the mid-1960s, U.S. mental health care has been directed toward provision of services thought especially bene

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beneficial to people labeled "chronically mentally ill." Focus has been on the deinstitutionalization[b] of "mental patients" (i.e., depopulation of state mental institutions) and development of a network of local Community Mental Health Centers (CMHCs). Mental health planners were to develop, then implement, treatment practices which deemphasized hospitalization (in state *or* local facilities). Comprehensive outpatient care in community settings was to provide vocational and social rehabilitation programs, consultation, and preventive mental health education (Brown 1985, 6) to augment deinstitutionalization schemes. These practices, discussed as early as the late 1940s and formally proposed to Congress in 1955, were delayed until 1965, when enacted legislation ensured federal payments to local providers of mental health care through Medicaid and Medicare public assistance benefits. (Deinstitutionalization and the development of the Community Mental Health network are discussed in detail in Chapter 4.)

Some beneficial changes associated with these practices have occurred. Probably the most dramatic difference resulting from the deinstitutionalization emphasis is the shortened length of the average hospital stay (Brown 1985, 5-6). The milieu-type therapies (first developed in Great Britain immediately after World War II) reaching the U.S. in the 1950s have been incorporated in local hospitals associated with Community Mental Health Center clients. This has a positive impact on hospital experience for some consumers. Additionally, U.S. practitioners' reliance on treatment with psychoac-

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tive drugs contributes to increased numbers of consumers permitted to live in community-based residences.

However, based on findings from this research, I contend that contemporary changes in practice, while beneficial to some consumers, cannot be characterized as generally effective for consumers' recovery of mental health. Moreover, mental health care practices which are demonstrably harmful (e.g., long-term use of psychoactive medications, electroconvulsive shock therapy)[1] have neither been abandoned nor curtailed. Reported symptomatic relief from some consumers and enhanced social control capacities for outpatient practitioners and hospital personnel facilitate continuance of these treatments. Improvements in the quality of some aspects of life for mental health consumers are not synonymous with development of capacities to achieve versatile social competence; develop congruous self and social identities; or sustain meaningful and satisfying social relationships which mark restored mental health.

Findings from this project reveal that U.S. mental health care in the contemporary period (i.e., the 1970s-1980s) reflects only slight effectiveness in enabling people deemed to be suffering from "chronic" or "severe mental illness" to recover abilities to freely pursue chosen life interests. There has been little advancement in rehabilitative efforts for deinstitutionalized patients over and above community-

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[1] For a comprehensive discussion of brain-damaging effects of such treatments see e.g., Peter Breggin (1979, 1983).

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based drug therapies, continued subsistence payments (i.e., public assistance disability benefits) for community residence, and vocational rehabilitation programs available through Community Mental Health Centers (CMHCs) that neither allow vocational placement nor social rehabilitation for the majority of mental health consumers using them. Psychotherapy is a cornerstone of community treatment, but vagaries of economic situations and workloads for practitioners in CMHCs result in frequent turn-over of therapists and/or long waiting lists for consumers desiring psychotherapy services. Additionally, consumers participating in this study who have been hospitalized repeatedly[1] report that social control efforts by hospital personnel (e.g., seclusion, physical restraint, forced injection of major tranquilizers) are a dominant feature in local hospital experiences. Those who are luckless enough to be returned to the still existing state hospitals when local hospitals refuse to admit them report this feature is exacerbated in state institutions.

Bureaucratically governed hospitals are conflict ridden by competing interests of administrators, practitioners, workers differentiated by location in the internal hierarchy, and the treatment needs of institutionalized patients (Grob 1983; Magaro et al. 1978; Chamberlin 1978; Rose and Black 1985). Competing interests are routinely resolved in favor of those highest in the bureaucratic hierarchy. Workers with the

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[1] This finding is a significant trait of the deinstitutionalization era, noted in Brown (1985, 76-7).

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least power have the most direct contact with patients, who have none.

Despite attempts to address these continuing problems in hospital settings through formalized policy, patients are still physically abused and subject to largely custodial care. This is especially true for public mental health consumers and/or for persons hospitalized in public institutions. Examples of this abuse presented by public consumers in this study included near suffocation; beatings; and cracked ribs during encounters with direct care workers at the bottom of hospital hierarchies. Verbal abuse of patients by these same workers is rife.

Features of contemporary community placement manifest less overt harm to consumers, but continue to be marked by features which do not restore mental health for all involved in treatment. This is despite consumers' remarkable perseverance in seeking, and actively participating in community-based mental health treatments (e.g., psychotherapy, vocational rehabilitation, psychiatric drug administration). Public assistance disability benefits (i.e., Social Security Administration supplemental income [SSI] or full disability income [SSD]) allow economically stressful subsistence only for some consumers. Others have been deprived of their benefits by governmental fiat or bureaucratic loophole. Public consumers' benefit checks are also frequently stolen from their mail boxes. When consumers cash their checks, they often become victims of crime. Community citizens may recognize their sometimes manifest inabilities to defend themselves and their

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property. These events frequently result in homelessness for involved consumers.[c] The additional burden of stigma, routinely levied against people known or suspected to be "mentally ill" frequently precludes equal employment or housing opportunities (if or when jobs or low-income housing are available). There is little demand for the labor of persons judged to be mentally impaired, and few land owners wish them as tenants.

Participation in the mental health care system does not alter consumers' largely degraded status in the community. Community based treatment has not allowed many consumers to develop coping abilities needed to maintain secure community residence. Long years of treatment and numerous enrollments in vocational rehabilitation programs have not restored abilities to pursue competitive employment for many public consumers. Thus, it is not surprising that critics argue that "because the mental health industry is financially dependent on "mental illness," there is no real reason to treat effectively" (Magaro et al. 1978, 159). Mental health care practitioners in the U.S. continue to rely on pharmacology, short-term therapies, and rehabilitation programs that do not rehabilitate as primary treatment modalities (Bloom 1984; Rose and Black 1985).

In this context, those who consume mental health services have joined governmental, professional and lay groups critiquing contemporary practices of the mental health system. During the 1970s and early 1980s, some consumers organized against the psychiatric establishment and took their protest to the

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streets, vociferously condemning psychiatric "treatments" such as psychosurgery, over-use of psychiatric medications, restraints, and seclusion (Madness Network News, 1974; 1977; 1981; 1982-3; 1983b; 1985; 1985b; 1986). Other consumers couch criticisms in terms of their own experiences, arguing for development of "patient-controlled" alternatives to mental health system offerings (Chamberlin 1978). Some recipients of care skirt the edges of the organized consumer movement for "mental patient liberation" (Brown 1985, 175), forming associations in local communities to address advocacy and recovery needs of consumers without formally participating in the larger consumer coalition. Alternatives By Consumers is one such community association.

ABC's inception in 1979 coincided with the advent of mental patient advocacy efforts in many areas of the U.S.. The collective and individual experiences of participants in ABC, their concerns, activities, and organizational entanglement with the formal mental health care system, reveal complexities involved in their efforts to provide a genuine community to peers in the care system. (My assertion that ABC represents an authentic community to mental health consumers is explored later in this chapter and also in Chapters 4, 5, and 7.) Alternatives By Consumers' robust organizational health today suggests that issues of concern to mental health consumers (especially those involved in the public system) have not waned over time.

Official recognition of the ineffectiveness of deinstitutionalization and outpatient treatment at Community Mental

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Health Centers from administrators and planners in the mental health system was delayed, and continues to be muted. However, during the early 1980s, some states (e.g., Michigan, Ohio, Indiana) sought redress to the continuing problems of persons labeled "chronically mentally ill" by providing funding to Departments of Mental Health, earmarked for distribution to "consumer-run alternative services."

Although Alternatives By Consumers was founded in 1980, the organization was not awarded funding under these provisions until 1982. However, it was still one of the earliest recipients of these grants. The organization continues to receive funds today because evaluations of their programs (see below) have convinced administrators in Department of Mental Health and legislators in the state Congress that ABC services to peers in the care system who share a "chronically mentally ill" label is effective.

In the "Michigan Department of Mental Health Research and Evaluation Division Final Evaluation Report: Drop-In Center, [Alternatives By Consumers] Inc., Clinton-Eaton-Ingham Community Mental Health Board," professional evaluators reported on data collected and analyzed during ABC's first year:

> [With respect to the 78.1% user satisfaction findings] ... This general satisfaction with the Center may be based upon the respondents' sense that they are making friends at the Center, they are becoming more self-sufficient as a result of participating at the Center, and they see that the frequency with which they help others mirrors almost exactly the rate at which they themselves are helped by others. ...Ninety per-cent of the volunteers completing the survey reported they were feeling better about themselves as a result of their volunteer work [at the drop-in] (Chamberlain and Barker, 12/22/86).

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People associated with the ABC organization report that their self-esteem has improved, their self-confidence is greater, and that they receive hospital care less frequently and/or their hospital stay is shorter when they are admitted.

Of the few consumers employed by the organization (and/or its satellites), some report great satisfaction in "getting off welfare," because they no longer have to depend on Social Security Administration disability benefits (i.e., SSI, SSD) as their sole source of income. Others begin by volunteering their services to ABC and are later employed there, and/or use their volunteer skills to seek competitive employment in the community.

While the numbers of people who reclaim or achieve vocational abilities through ABC involvement are small, it is significant that these events occur at an organization developed and operated solely by and for mental health consumers deemed to be "chronically mentally ill." Of greater import are the reports of enhanced social competence and development of meaningful social relationships which are more widely shared among ABC consumers. These provide some markers of the effect that the ABC community has on participants' abilities to reclaim their mental health. ABC has provided what specifically targeted practices of the mental health system (i.e., deinstitutionalization and Community Mental Health Center services) could not provide: effective help to "chronically mentally ill" consumers in the areas of social and vocational rehabilitation.

How and why are practices of mental health professionals la

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largely ineffective in treating people labeled in this way? How and why have ABC consumers sometimes succeeded where professionals have not? How does the work of the Alternatives By Consumers organization and the trend it represents (i.e., funding for consumer-developed alternatives) intersect with the formal system of mental health care? As these questions are explored, the impact of structural forces on individual consumers; the work of the ABC organization; and the mental health care system becomes salient. Macro level forces, as well as social forces operating at the level of the individual, affect mental health care experiences. Traditional practices within the care system, directed by structural interrelationships, affect situated actors and impinge on the nature of mental health consumerism.

Structural relationships in U.S. advanced capitalist society are marked by "socially constructed definitions of reality" (Berger and Luckmann 1967, 81) which are informed by material conditions. Dominating social constructions of reality and material conditions affect actors in differentiated social positions in certain ways. The mental health industry, as an integral sector in the U.S. political economy, embodies institutionalized processes (e.g., professionalism, mentalism, racism, sexism, classism, ageism) (Hill 1983; Wineman 1984) that structure and reproduce the professional experience of caregiving as much as it structures and reproduces individual experiences of receiving care.

Professional practice in psychiatry and related mental

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health care professions is shaped by economics, politics, mainstream ideologies, and allegiance to institutional arrangements that maintain the "mental health industry" (Magaro et al. 1978) in U.S. society. Rote practices in the care system sustain ideological, political, and economic institutional linkages that characterize its workings. At the same time, professional practices are affected by institutional allegiances and prevailing political-economic emphases. Critiques of contemporary practices reveal that institutional linkages maintaining the mental health system status quo <u>also</u> symbolize the problems besetting that system.

For example, deinstitutionalization has been depicted as an "attempted transfer of financial responsibility" (from state to federal budgets); "a transfer of responsibility from public authority to private control" (i.e., from government regulated mental institutions to unregulated boarding homes or poorly regulated nursing homes); a transfer of care to locations which "retain traditional forms of personal control and institutional rigidity" (i.e., in local hospitals and nursing homes); and a contributing factor in the "transformation of public perception of clients from mental patients to welfare cases, thus demeaning them more than they already are" (in Brown 1985, 8-9).

States' <u>economic</u> <u>interest</u> in saving costs associated with institutional care fueled <u>political</u> <u>efforts</u> to enact legislation that would provide subsidy to <u>institutions</u> providing care. It is important to note that the institutions involved in receiving monies for care provisions are both *physical* (e.g.

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(e.g., Community Mental Health Centers, nursing homes and local hospitals), and *occupational* (e.g., institutional and community psychiatry and related mental health care professions; and educators who train practitioners at institutions of higher learning).

The ideology that legitimates institutional or outpatient care for the typified mental patient/welfare case depends on notions of "mental illness" as a condition requiring medical treatment by professional experts (i.e., psychiatrist-M.D.s). The interrelationships between ideologies that justify and explain the role of mental health practitioners and typifications of "mental patients" are integrally bound to political and economic considerations that enable and constrain all actors in the mental health care arena (i.e., recipients and providers).

The effects of these processes are realized in the experiences of mental health consumers. Major processes of concern here are: contemporary practices and "policies" of the mental health system; the operationalization of those practices by mental health professionals and workers in various locations of the system's bureaucracy; the connections between institutions of care, occupation, government, and education, and practices of people associated with all; dominant political-economic interests of decision makers affecting operations of the care system; individual practices of therapists that unwittingly incorporate pervasive ideologies of mentalism, sexism, racism, classism, and/or ageism. Their effect is filte

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filtered through the personal circumstance of each consumer, but each process contributes to the collective experience of mental health consumers in this country. Consumers' "private troubles" are "public issues" which have been disguised by the usual portrayal of their experiences. The goal of this project is to remove the veils which keep this reality disguised.

Purpose of Project and Research Questions

The overarching purpose directing my research efforts in this project was to reveal the nature of contemporary mental health consumerism. In my attempt to ascertain these dynamics I formulated the following questions, which guided my research efforts:

1. Natural history of ABC: What are the origins of this organization? What interpersonal and inter-system (organization-to-system) dynamics are at work in its daily operations? In what ways do ABC advocates interact with and/or confront the professionalist system of mental health care? What kind of activities has ABC initiated to change the traditional care system?

2. Nature of consumers' experiences: How do consumers describe their experiences in the mental health system (private or public)? How do they describe their experiences at ABC?

3. Institutional intersection with personal biographies: Has consumers' participation at ABC changed the direction of their "careers as mental patients"? Has it raised issues of definitions about concepts like "mental illness" and their own diagnoses? Has it altered their experiences or views of the mental health system?
   Based on their experiences, what critiques do consumers offer about the workings of the system and the programs they've participated in (including ABC)? Do consumers' experiences in ABC challenge, support, and/or change the dynamics in the political economy of mental health care? Are there unintended consequences for consumers, the community, or the mental health care system resulting from ABC's community activities?

Through in-depth interviews with ABC mental health con-

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sumers volunteering to take part in this research project,[1] I explore the complex nature of the formal mental health system. I ask interview volunteers their appraisal of treatment practices (inpatient and outpatient), policies, programs and diagnostic definitions that have affected them throughout their long years of involvement in the mental health system. I also ask consumers to describe their experience with the ABC organization and reflect on its positive and negative aspects.

A case study of ABC, depicting the organization's natural history, is another major component of this project. For this part of the study, I analyze field notes taken at the organization during 1983 and 1986.[d] I also draw upon my knowledge of significant events and mundane routine I learned about while an employee of ABC (1986-1988). The case study also incorporates relevant data compiled through documentary research and selections from the interviews.

In these ways, attentive to the vantage point of ABC participants, I explore the nature of ABC advocacy efforts, the nature of consumers' experiences at ABC, and the intersection of personal biographies with the traditional mental health system and the consumer-run organization. How and why the need for an ABC organization arose, how it challenges the institution of mental health care while it straddles that system, and how ABC's internal and external workings have

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1.My research proposal and strategies for data collection, including in-depth interviews, were reviewed and approved by the Michigan State University Research Committee Involving Human Subjects (May, 1987) before any data were collected.

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affected the "mental patient careers" for its participants comprise substantive concerns in this study.

I integrate these substantive findings with theoretical formulations that bridge consumers' personal experiences to treatment experiences; treatment experiences to mental health professionals' practices; professional practices to ABC practices; and practices of both entities (mental health professionals and ABC consumers) to the workings of the U.S. political economy. These factors interrelate. Without attention to _each_ link, it is not possible to understand the situation of either professionals or consumers. These interrelationships direct the experience of mental health consumers and the practice of professionals.

The Research Setting

Alternatives By Consumers was founded by one man following his psychiatric hospitalizations for "borderline schizophrenia" in the late 1970s. He realized, first hand, that the inpatient and outpatient programs available in the community designed to aid recovery from "mental illness" were neither appropriate nor effective for large numbers of consumers. His dedication to changing the conditions for consumers in the mental health system inspired other recipients to join him in pursuit of advocacy and self-advocacy efforts, and resulted in the incorporation of Alternatives by Consumers.[e]

ABC is today a non-profit organization devoted to assisting consumers living in or returning to community settings follo

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following psychiatric hospitalization. The organization and its various programs (i.e., the "Help Project" and Drop-in program housed in the Lansing ABC Center; and the OUR Project with offices in East Lansing)[1] are run solely by both former and current consumers of the mental health care system. Its major goal is to "deinstitutionalize" the consumers who use their programs, i.e., help consumers recover from the "institutional syndrome"[f] (also called institutionalization) that is a frequent by-product of psychiatric hospitalization. Through advocacy efforts and acquisition of self-advocacy skills, organization leaders hope consumers will become empowered, thus reducing the need (and/or length of stay) for psychiatric hospitalization and rehospitalization.

Alternatives By Consumers was incorporated in 1981. Steven Ashton, its founder and Executive Director, began volunteer advocacy efforts and set-up ABC's first office with his personal funds. In the intervening years, the organization has received recognition, encouragement, and eventually, funding support from the Michigan Department of Mental Health (DMH) and the local Community Mental Health Center (CMHC) currently operating in Lansing, Michigan. Funds are received under a "consumer-run alternative programs" allotment provided by state legislators and funneled through the conduits of the DMH and CMH to the organization. ABC is also the only consumer organization in the state to receive a yearly grant for operations from the local city government.

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[1] Details on ABC programs are provided in Chapter 5.

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Largely through a consumer "grape-vine," ABC is recognized as an authentic alternative to professionally-staffed mental health care programs in the Greater Lansing community, and honors a myriad of requests for assistance and/or advocacy to over 900 consumers per year, whose numbers increase annually. Nearly all consumers who volunteer or use their services bear the label "chronically mentally ill." Staff people are also consumers and/or have experienced severe coping difficulties in their past. Some staff have been inpatients in state or local psychiatric hospitals, and most continue in psychotherapy of some kind.

ABC has a unique structural position in the mental health care system. Developed and operated by consumers, it offers a challenge to the "professionalist ethos" (Freidson 1970) of mental health care by provision of services and support on a peer-to-peer basis. Yet, a guiding tenet of its work is "non-interference with the formal therapeutic relationship" ("First membership flyer," ABC internal publication 1983). Offering support to individual consumers voluntarily undergoing mental health "treatments" whose efficacy many ABC consumers question, creates recurring tension in their advocacy efforts with practitioners and administrators.

This is not the only structural paradox that ABC manifests. Other structural strains and accommodations connected to the work of this organization are revealed through qualitative analyses of interview data and documentary research methods. To ascertain unacknowledged and unintended conse-

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quences for both the organization and the mental health system, data are surveyed from a wide variety of theoretical viewpoints.

Theoretical and Methodological Framework

Qualitative analyses of experiences of ABC consumers reveal that the nature of mental health consumerism is affected by the intersection of micro level experience with macro level social forces. The interrelationships between individual biographies; type and duration of specific mental health treatments received; intensity of involvement with the workings of the ABC organization; and the political, economic and ideological trends and conditions of U.S. society impinge on consumers' experiences.

These interrelationships comprise focal theoretical concerns of this project for three reasons. First, macro level exigencies shape, and frequently direct, consumers' experience in specific ways. For example, as noted earlier in this chapter, the practice of deinstitutionalization has shortened the average length of a psychiatric hospital stay. Deinstitutionalization was a practice defended as a means to cut costs of institutional care.[1] As a cost-saving measure, consumers may thus be discharged from hospitals earlier when deinstitutionalization practice is emphasized.

Secondly, macro level exigencies interact with the per-

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sonal and historical circumstance of individual consumers (e.g., early discharge may return consumers' without economic support to abusive family situations). Without attention to this macro level-micro level interaction, broad comprehension of mental health consumerism is precluded. Thirdly, it is the specific interplay of institutional processes with personal biographies that affects possibilities of resolving conditions labeled "mental illness," (e.g., women, members of ethnic and racial minorities, children and elders, foreign-born persons, and persons with limited formal education are disproportionately hospitalized, diagnosed as "severely mentally ill," and subjected to invasive treatments known to cause irreparable harm [cited in Hill 1983, pp. 258, 267, 282, 316, 353-6]).

Analyses of theoretical focal concerns are directed toward integrating the discovered "grounded theory"[1] of mental health consumerism with theories that illuminate the nature of this interplay for individuals participating in the Alternatives By Consumers organization. Using this grounded theory as a conceptual springboard, the relationship between mental health consumerism and other experiences of social disadvantage expedites conceptualization of a "substantive general theory" (Glaser 1978), which I have called "a theory of social vulnerability states."

Many theoretical perspectives have been brought to bear

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[1] This refers to a qualitative data analysis methodology developed by Glaser and Strauss (1967). Additional details about the methodology can be found in Chapter 3.

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on this research project: political-economic; sociology of knowledge; critical theory; feminist theory; phenomenology; and symbolic interactionism have been particularly useful. Application of various theories to research findings inform (but do not direct) my data analyses and policy/practice recommendations I offer in conclusion.

During early literature reviews for this project, I found that the kinds of questions posed by researchers in the field of mental health, the choice of people (or documents) researchers choose to consult, the interpretation of research findings and the selected research endeavors that are funded, all relate to tacit assumptions held about the population of mental health care consumers ("mentally ill, chronically mentally ill") and their cadre of treaters (professional "experts").

Reliance on unquestioned typifications about the nature of people and their respective attributes is routinely affiliated with processes of institutionalized racism, sexism, and classism (among others). In practice, people in devalued social categories experience the effects of these processes in interaction with others as discrimination.

When seen from the consumer vantage point, this dynamic clearly paralleled many experiences of women elaborated by feminist scholars, and equally applied to a diversity of social situations (e.g., the family, treatment settings, job sites). Use of feminist theory provided me with insight into the ways in which concrete experiences can be erased and demeaned.[9] Feminist theory also guided me toward other complement

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Feminists' challenges to develop an "alternative way of thinking sociology" (Smith 1987, 91) in the context of existing research which routinely discounted, ignored or distorted consumers' communications indicated the need for phenomenological inquiry (e.g., Rogers 1983) as a centerpiece of qualitative research methodology.

Women's perspective, Smith argues (1987, 91), discredits sociology's claim to objective knowledge independent of the situation of the observer within the discipline, or of the discipline's position in society. "Its conceptual procedures, methods, and relevances" (Smith 1987, 91) are prioritized: "Issues are formulated as issues which have become administratively relevant not as they are significant first in the experience of those who live them" (1987, 87).

Smith's suggested resolution to this dilemma underscored my decision to use a phenomenological approach in my research: "If sociology cannot avoid being situated, then sociology should take that as its beginning and build it into its methodological and theoretical strategies" (Smith 1987, 91).

Research seeking to unravel the essence of "situated meaning and talk," a goal of phenomenological inquiry, would allow the intentions of social actors in research settings primacy and voice. This was facilitated by a "grounded theory" methodology (Glaser and Strauss 1967), which embodies many phenomenological tenets in practice.

Application of ideas broached by sociology of knowledge

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theorists (e.g., Berger and Luckmann 1967; Mannheim 1936) facilitated integration of social reality constructs, codified in the data, with central features of overarching "social relevances"[1] peculiar to the sociocultural context of U.S. society. Attention to Marxist theory (e.g., Marx and Engels 1978) and critical theorists interested in the operations of the political economy (e.g., Giddens 1979, 1983; Bernstein 1978; Habermas 1971, 1973, 1979; Scull 1977) allowed identification of ideological, political and economic underpinnings for ideas about "mental illness" and "mental patients."

Below, I review the materialist perspectives employed in my project (i.e., political-economic and sociology of knowledge), briefly touching on issues illuminated by phenomenological theory. I put this research project in sociohistorical, sociocultural context by linking theories used to applicable social trends and practices which affect the nature of mental health consumerism in this country. I structure the discussion according to the predominant orientation of theorists cited in various camps, despite areas of overlap.

Materialist Theories: Focus on Structure

The material conditioning in institutionally favored definitions of "mental illness" is well analyzed within a political economic framework. As Richard Warner argues in

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[1] "Knowledge of everyday life is structured in terms of relevances. ... Basic relevance structures referring to everyday life are presented ... ready-made by the social stock of knowledge ... objectivated in American society (Berger and Luckmann 1967, 45).

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Recovery from Schizophrenia: Psychiatry and Political Economy (1985), a political economic analysis can enlarge the social vision of conditions judged to be "chronic mental illnesses,"[h] such as schizophrenia.

> A materialist strategy allows us to generate the hypothesis that social attitudes towards the insane partly reflect the usefulness of the psychotic in the productive process; that psychiatric ideology is influenced by economic conditions; that the course of schizophrenia is influenced by class status, sex roles and labor dynamics; or that variations in the prevalence of the illness may reflect differences in modes of subsistence and production ... Material conditions [do not] *create* schizophrenia in any simple, deterministic way, but rather they *mold* the course and outcome of the illness and *influence*, along with other factors, its prevalence (Warner 1985, 1, 3). (Emphasis in the original.)

Warner's application of a materialist strategy to his cross-cultural study documents the thesis he outlines above. Social definitions of the nature of the people, the problem from which they suffer, and concordant "treatment" recommendations, fluctuate cyclically with the "health" of the economy. The condition labeled schizophrenia has been deemed curable by mental health professionals during times of labor demand and incurable during times of labor surplus:

> Efforts to rehabilitate and reintegrate the chronically mentally ill will only be seen at times of extreme shortage of labor--after the other battalions of the industrial reserve army have been mobilized (Warner 1985, 137).

This dynamic contributed to a delay in U.S. rehabilitative efforts for institutionalized persons following World War II, when their labor was not needed (reviewed in Chapter 4).

Long-term cross-cultural trends also reveal that during cyclical economic depressions, genetic/hereditary and biological factors are investigated as important causes of psychosis;

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institutionalizing persons labeled "mentally ill" is judged therapeutic; and physical, surgical and pharmaceutical treatment methods are deemed most valuable (Warner 1985, 138). Professional consensus on these same issues shifts dramatically when the economic cycle hits a boom period: social factors are scrutinized as important causes of psychosis; psychosocial treatments are valued; institutionalization is deemed harmful; and treatment efforts intensify for people thought to be "severely mentally ill" (Warner 1985, 138).

Other structural analysts uncover similar trends (e.g., Brenner 1973) in social consensus concerning people labeled "mentally ill" that fluctuate with the state of the economy. Brenner found that the tolerance of "deviant" behaviors in communities oscillates with economic cycles: tolerance increases during times of prosperity (Brenner 1973, 199). In contrast, "those low on the socioeconomic ladder are the prime candidates for institutional treatment, and their visibility increases as economic conditions deteriorate" (Brenner [1973] in Magaro et al. 1978, 4).

Contemporary practices reveal the enduring nature of this trend. Emphasis on non-institutional, psychosocial treatment in the U.S. (i.e., depopulation of state hospitals and development of community mental health programs) coincided with the economic prosperity of the late 1960s and early 1970s. As unemployment rose during the late 1970s and economic policies of the Reagan era spawned cut-backs in public assistance programs and recession during the early 1980s, deinstitutionalization practices came under fire from those arguing for prote

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One example of this structural trend is seen when Congressional attention focused on the connection between deinstitutionalization practices, diminished public assistance provisions, and ensuing homelessness.[1] Another is found by examining urban policies developed to address mounting numbers of homeless people thought to be "mentally ill" in cities across the U.S.

In New York City, for example, efforts to round-up homeless people adjudged "mentally ill" through a "mobile outreach program ... with special authority to transport individuals for psychiatric evaluation on an <u>involuntary</u> basis" (Baxter and Hopper in Lamb 1984, 117) intensified during the recession of the early 1980s. Prior to 1982, no involuntary "outreach" procedures were allowed.[1] As the recession grew worse, institutional treatment was targeted for people visibly impoverished.

The "mental health industry" (Magaro et al. 1978) is an integral part of the U.S. political economy. The preceding example illustrates this. Demands for involuntary institutional treatment of the visible poor are supported by federal subsidies to the industry (via federal Medicaid/Medicare payments to providers and institutions for persons inculcated into the system) and less tangibly by the dominant political

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[1] See, for instance, "Hearings on the Homeless in America," transcripts of hearings before the House Committee on Banking, Finance and Urban Affairs and the Subcommittee on Housing and Urban Development, 98th Congress, January, 1984.

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conservatism of the times. The image of change in mental health care, including the alleged institutional protection accorded by forcing care on the indigent, is largely illusion.

> [D]espite the public image of dynamic new therapies, drugs, and community outreach procedures designed to overcome the problems of "mental illness," there is every indication from within the [mental health] industry itself that only the social form of the problem has changed (Magaro et al. 1978, 161).

As consumer groups become officially recognized mental health care organizations, it is important to analyze the unique, and often contradictory, structural position these associations assume in the overall professionalist and institutional framework of medical mental health care. ABC's relationship to existing structures of mental health care produces both structural strain on the system (e.g., by challenging professionals' definition of consumer situations) and institutional accommodation from the system (e.g., in the form of funding). If the advocacy efforts of Alternative By Consumers' participants affect the social form of the problem mental health professionals address, does funding to ABC sow the seeds of the system's eventual demise? Does ABC's acceptance of that funding elicit (witting or unwitting) accommodations that undermine organizational objectives? The nature of this intersection may determine future practices of mental health professionals and consumers alike, and influence social order and/or the ethos of political conservatism that have heretofore sustained the "mental health industry."

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Sociology of Knowledge: Focus on Ideology

It is argued (e.g., Leifer 1967) that ideological support for political conservatism in mental health care relies on medicalizing the social problems of the poor and/or otherwise socially disadvantaged persons. History reveals that psychiatry and related mental health care professions set the stage long ago for this ideology--"a complex of ideas which direct activity toward the maintenance of the existing order" (Mannheim 1936)--to take hold.

> The medical model [of "mental illness"] implicitly supports conservative social policies, because it defines social deviance as a sickness and justifies maldistribution of therapeutic resources in the names of research, training and chemotherapies that provide dubious "therapy" but make patients manageable and support a $100-million-per-year drug industry (Leifer [1967] in Magaro et al. 1978, 171).

Social belief in the idea/ideology of "mental illness" as an authentic illness which parallels physical illness constructs a certain reality: "mental patients" are different, sick, chronically disabled, dangerous, unpredictable, and/or deviant from others in mainstream society. When categorized as people with aberrant genetic make-ups, they pose no challenge to social understanding of the phenomena (i.e., an involuntary "illness"), nor its appropriate control (i.e., medical treatment and/or hospitalization).

By social consensus (informed by "mental illness" ideology), people labeled "mentally ill" are seen as "non-normals," most appropriately treated by those with expert knowledge about the allegedly mysterious and complex maladies they manifest (i.e., mental health professionals). People suspected

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of harboring "mental illness" are also appropriately brought to the attention of the historical experts (Grob 1983; Mauss 1975) in defining presence or absence of "mental disease." Thus,

> psychological theories [enter] everyday life by providing the interpretive schemes for disposing of problematic cases. ... The psychological theories then serve to legitimate the identity-maintenance and identity-repair procedures established in society, providing the theoretical linkage between identity and world, as these are both socially defined and subjectively appropriated (Berger and Luckmann 1967, 177).

Hence, for the good of society and their own well-being, people who cannot fend for themselves in social settings must defer to policy and treatments developed by professional experts (i.e., "the identity-maintenance and identity-repair procedures established in society"). This social understanding legitimates forced care of people so labeled: both society and "mental patients" are protected when "mentally ill" people are segregated in hospitals and/or forced into institutional or outpatient care.

In contemporary practice, the influence of the present-day political, economic, and institutional climate is obscured by ideological claims to medical or scientific objectivity[3] in determinations of "mental illness." Professional practices maintain the ideology of "mental illness" (e.g., through diagnostics and somatic treatments) <u>and</u> the social order (e.g., through institutional and/or pharmacological control of the "mentally ill," including expert witness testimonials in criminal courts). Moreover, their practices and the institutional arrangements that facilitate them (e.g., hospitals, cou

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courts of law, Congressional funding appropriations for the mental health system), perpetuate belief in the expert knowledge of professionals.

The personal situation of the practitioner (i.e., marital, racial, class, or gender statuses; sexual or political orientations) which conditions the world view communicated to those consulting him or her, is belied by claims to professional objectivity (or emotional neutrality) and expertise in treatment settings. As professional experts, their view of the individual in treatment is allegedly uncolored by their own situations, and their view of social dynamics affecting the individual deemed accurate.

> [Survey research indicates that] treaters seek and value social adjustment above a host of other possible goals. ...In this culture it is likely that [therapists] will adopt the patterns and goals that will serve [their] own and society's goals, as opposed to [their] client's needs. ... In defining mental illness from the perspective of social values and deviance, ... the 'psychologizing' that serves to enforce social control reinforces the therapist's position as "normal" or "right" (Magaro et al. 1978, 172-3).

In this process, "the individual as locus of the problem precludes the investigation or validation of problems lying within society" (Magaro et al. 1978, 173). Thus, the conservative social order remains undisturbed as the complex of activities characterizing the mental health industry maintains the stats quo:

> Decisions about who is mentally ill or mentally healthy are determined, not by any scientific standards, but rather by the social, moral, and political standards of the day personified by the professional ... The psychotherapeutic establishment effectively transmutes social rebellion and discomfort into psychological or intrapsychic difficulty (Magaro et al. 1978, 172-3).

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What is particularly insidious about certain ideologies for consumers is the depth to which they are internalized and thus removed even further from consciousness. Accepting professional communications which rely on an ideological conception of "mental illness" posed in biological givens makes it less possible to entertain alternative definitions of self-identity. Continued exposure to such conceptualizations decreases individual potential for critical self-reflection about them.

Typifications of people deemed to be "mentally ill" are not only found within medicine, academia, or depicted in literature and mass media. They are recreated and perpetuated through <u>internalized</u> social definitions embraced by the general public and consumers alike (Berger and Luckmann 1967, 176).[k] Typifications are embodied in the social stock of knowledge specific to particular societies/social formations. Societal members unwittingly rely on these typifications when seeking to explain or understand phenomena deemed "mental illness."

Consumers who have been hospitalized repeatedly undergo a total resocialization (Goffman, 1962), becoming the "mental patients" they are believed to be. My field-work observations record the entrenched nature of what I call the "mental patient mentality." It is a tacit acceptance of definitions of self that are grounded in their social identity as a "mentally ill" person or "mental patient." It reifies the larger social phenomenon sometimes referred to as "mentalism."[1] Consumers refer to themselves and peers as "mental patients." Once

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resocialized to this new identity, the need to reflect on what they may have accepted as the reality about their situation or "self" is greatly diminished, if not extinguished. Their "career as a mental patient" (Goffman, 1959) has begun. "Psychologies produce a reality, which in turn serves as the basis for their verification" (Berger and Luckmann 1967, 178).

These patterns have special importance when seen from a sociology of knowledge perspective. To explore the impact that consumer-to-consumer care has on existing practices, it is necessary to ground the problem in a sociohistorical context and see if the difference in practice makes a difference in outcomes (i.e., in recovery of mental health for consumers). What new "social constructions of reality"[m] are created by the advent of groups like ABC? Do new reality constructions about consumer groups and/or individual consumers acting as advocates for their peers alter the workings of the formal system of mental health care?

In some advocacy efforts, the activities of ABC consumers seek redress on behalf of--or in conjunction with--peers who wish to refuse treatments prescribed for them (e.g., hospitalization, administration of major psychiatric drugs). And yet, one-to-one consultations with consumers manifesting extreme vulnerability or coping difficulties (e.g., fearful of others; afraid to leave their homes or ABC, once there; without adequate food or shelter which they aver is "their fault") are characterized by attempts to alter definitions of the problem. Consumers at ABC assuming the role of advocate to persons

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visibly upset offer alternative understandings to the person involved. Examples may include: "Maybe you are afraid today because you argued with me yesterday;" "When they kicked you out of the shelter, wasn't it because your "meds"[1] made you pace all night? Why is that your fault?" Attempts to alter definitions of "mental patients" and/or "mental illness" are also seen in contacts with family members who call for ABC advice on problems with individuals in their homes, and in public presentations about these issues.

In these respects, advocacy work is directed toward modifying the ideology of "mental illness" <u>and</u> practice in the name of a generalized belief. Namely, psychiatric labels are harmful because they cloud vision of the real situation (a person who is having problems versus a "schizophrenic" becoming "ill" thus requiring medical treatment with drugs or hospitalization).

However, ABC advocacy efforts, when situated in their life-world context, also manifest tensions and contradictions in consumers' efforts to modify the ideology of "mental illness." These were revealed through phenomenological inquiry.

Phenomenology: Focus on Situated Meanings

An historical practice within the field of mental health has been the routine discounting of consumers' communications to practitioners and researchers (if or when consumers are

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[1] This is mental health consumers' vernacular for psychiatric medications.

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consulted). Largely an attribute of the imposed definition of "mental illness" on consumers' situations, this prevents consumers' important contribution to professional knowledge about the nature of social conditions disguised by the label "mental illness." To enable change in professional practices which might _effectively_ address the needs of people labeled "chronically mentally ill," it is vital that consumers be given entree to the discourse of mental health care and practice.

Using phenomenologically oriented methodology[1] (i.e., "grounded theory" [Glaser and Strauss 1967]), the consumers' vantage point can be integrated with extant theoretical perspectives without compromising the integrity of their unique contribution. The process of discovery that this methodology embodies offers this protection. That is, grounded theory emerges from the data collected, when patterns of activities or behaviors coalesce to reveal themes relevant--or problematic--to the studied population. Thus, it is theory generated to account for patterns in the collected data, which reflect everyday life experiences in specific context.

Organizational activities of ABC consumers may be illuminated in some ways by a political economic framework, or a sociology of knowledge framework, but these analytical guides cannot account for _all_ patterns that emerge through qualitative analyses.

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[1] I base this claim on an analysis of phenomenological tenets and their convergence with procedures specific to grounded theory methodology which appears in Chapter 3.

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> We cannot adequately understand "social things," including human acts, by referring only to other things or facts. "I do not know a tool without knowing the purpose for which it was designed, a sign or symbol without knowing what it stands for in the mind of the person who uses it, an institution without understanding what it means for the individuals who orient their behavior with regard to its existence" ... Sociologists' *only* access to social structure is actors' action and talk. No alternative sources of data exist for social scientists; people must act or speak before sociologists can move toward understanding social reality in some way and to some degree (Rogers and Schutz in Rogers 1983, 146). (Emphasis in the original.)

Informed by this phenomenological understanding, I argue for the need to "bracket the natural attitude" toward people labeled "mentally ill" when undertaking research in their "life-world" context.[n] The need is as great when seeking to understand the viewpoint of practitioners, hospital personnel, administrators, or relatives of consumers insisting on committing loved ones to mental institutions. There is also need to articulate the varied meanings constructed by social actors affected by operations of the mental health care system. While societal members share access to the social stock of knowledge that accounts for conditions called "mental illness," specific viewpoints are conditioned by differentiated positions in the social order.

The voices silenced by routine practice of mental health care, however, most need to be heard: without their contribution, existing knowledge of psychiatrically labeled situations will not advance. Historically, consumers have been discounted: their social vulnerability renders them powerless in professionlist settings; social definitions, internalized and externalized, tell them they are "mentally ill;" and

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medical/psychiatric ideologies unilaterally determine/legitimate their subsequent treatment in the care system.

To give consumers voice by reporting their meaning-making activities and soliciting their critical views is to bring new light, and the hope of new relevant theory, to continuing problems of treatment and recovery for "the most vulnerable population there is."[0]

Research Methods and Practices: An Overview

To collect data for this project, I used documentary (non-statistical content analysis) and field-work methods (participant observation in field settings with in-depth interviews). From the accumulated data, I constructed the case history of the Alternatives By Consumers (ABC) organization. Data were also used to describe and analyze the social realities of community life for (self-selected) mental health consumers participating in the organization.

In the interviews,[1] as I explored consumers' understanding of "mental illness" and their own diagnoses, I tried to ascertain the ways in which they relied on or departed from social definitions routinely applied to their situations. In analyses of the data, I note the vehicles used by practitioners to communicate normative definitions and how they are received by the people affected.

As this project evolved, it became clear that understanding my collected data was possible by devising a comparative

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1.For the full text of the interview guide used, see Appendix A.

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scheme of "social reality constructions" used by persons volunteering to be interviewed; embodied by activities noted in field observations; and offered by professional players in the mental health care arena. Using the constant-comparative method advised by grounded theory proponents (Glaser and Strauss 1967; Glaser 1978), every line of data collected (in field notes and interview transcriptions) was coded according to the dominant "social reality construction" it revealed. Codes for recurring social-psychological processes (e.g., interactional dynamics and personal or social behavior patterns) were also included in coding categories.[1]

While not as rigorous as the coding procedures used for this project, I had previously coded field data collected at Alternatives By Consumers in 1983, and written a summary paper informed by those analyses. That study contributed to my early research preconceptions concerning this project. Only after I had worked as an employee of ABC (1986-1988) and completed several of my in-depth interviews with ABC participants did the convergence between macro-level and micro-level phenomena became apparent.

Triangulating all methods used (i.e., literature reviews, field research, case study findings and interview analyses) led me to understand specific ways in which the effects of social degradation or erasure, social typification, ineffective mental health care in bureaucratic settings, noxious

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[1] See Chapter 3 for detailed descriptions of the coding process.

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interpersonal relations, and the ideologies, economics, and politics involved in mental health care practice and policy were integral to comprehension of consumers' experiences.

These research practices were arduous. Time-consuming and complex in their interrelationships, it seemed they would never coalesce in an integrated way. My perspective on linkages and interactive effects of political economy dynamics; personal biographies of ABC consumers; mental health practices; treatment experiences; and consumers' experiences at ABC, emerged in bits and pieces. Each time I was <u>sure</u> I had reached a theoretical impasse, oppressive despair gave way to surprisingly sudden insight. Finally, it meshed.

I found that overarching critiques of the "therapeutic model" (e.g., Bellah et al. 1985; Masson 1988); suggestions that the workings of the mental health system could be completely subsumed by theories of "social control" (e.g., Hill 1983; Chamberlin 1978); or the consumer experience understood solely by analysis of "symbolic interactions" (e.g., Goffman 1962) were simply not sufficient to explain the totality of the consumer experience. Nonetheless, each perspective is a <u>necessary</u> component for understanding mental health consumerism and/or the effects of social vulnerability manifested by mental health consumers.

By focusing on these linkages, rejecting single-focus critiques, and attending to concrete experiences and meaning-making activities pursued by consumers, the major premise and theoretical supports for the grounded theory of mental health consumerism emerged.

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<u>Overview of Research Findings</u>

I have incorporated the key finding of this study in the major premise of the "grounded theory of mental health consumerism." Namely, *mental health consumers relieve social vulnerability by embracing a supportive community where definitions (or redefinitions) of situation or self are available.* This premise is supported by data for this project.

Qualitative content analyses of data during research at the Alternative By Consumers organization revealed that the careers of mental health consumers are best conceptualized by attention to their experiences of social vulnerability, to the level of connection they are willing and able to make to a community, and to their subsequent embrace, rejection, or ambivalence toward the definitions of situation/self available to them in that community. Moreover, understanding mental health consumerism requires attention to features of the political economy (e.g., labor market segmentation, institutionalized "isms") that create structural pockets where social vulnerability is rife (e.g., low-income urban areas with high unemployment). These features exacerbate social vulnerability generated predominantly through noxious interpersonal interaction. Their effects are realized in characteristic socioeconomic situations of mental health consumers.

I attempt to elevate the conceptual level of this theory, as suggested by Glaser and Strauss (1967), to approach a "substantive general theory," seeking to apply a specific grounded theory (e.g., mental health consumerism) more broad-

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ly. I have termed this latter effort "toward a theory of social vulnerability states," because key features of mental health consumers' experiences overlap with features of any experience of social disadvantage within given political economic structures. On-going social disadvantage embodies notions of social vulnerability, inequitable power relations, need for resolution of social vulnerability through community embrace, and similar vehicles for its resolution (i.e., access to positive definitions of situation/self; supportive communities; level of investment in communal activities; willingness or ability to embrace new definitions offered). (I outline key features of this grounded theory below. A more elaborate discussion appears in Chapter 9.)

Social vulnerability may be manifested in a variety of ways, but in its simplest form it is best described as generalized coping difficulties that result in inequitable social relations (i.e., these difficulties render an individual less powerful than others who are not experiencing social vulnerability). Experienced social vulnerability impedes efforts to achieve versatile social competence; develop congruous self and social identities; or sustain meaningful and satisfying social relationships. These capacities exemplify the resolution of social vulnerability and/or restored mental health.

Unrelieved social vulnerability is marked by inveterate emotional and social accommodations, i.e., a "social vulnerability state." Further, experiences of social vulnerability are reciprocally reinforcing. Age-related social vulnerability

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(e.g., for the very young), a shared human attribute, may be increased by occupying certain disadvantaged or demeaned social positions in advanced capitalist societies. As Wineman (1984) points out:

> Corporate capitalism is one of several inter-related and interacting structures of domination (based variously on ownership of the means of production, race, sex, sexual orientation, age, educational achievement and professional standing) in a total society pervaded by an ethic of dominant/subordinate power relations (Wineman 1984, 33).

Thus, social vulnerability is increased for occupants of the social structure who do not own the means of production, who do not share the dominant heterosexual orientation of the society, who have not attained a college or higher education degree, and who are affected by institutionalized racism, sexism, ageism, and professionalism.

The experience of social vulnerability intensifies for occupants of more than one devalued position. In U.S. society, to be a poor woman of color; underemployed, unemployed or out of the work force; and/or a client of the public assistance bureaucracy increases the likelihood that extreme social vulnerability or coping difficulties will be realized. If these conditions continue, it is likely that a "social vulnerability state" will characterize the experience of the individual. It will be manifested by emotional and social accommodations to this continuing reality (e.g., low self-esteem, deference to authority figures). Resolving social vulnerability is complex and problematic for people experiencing this "layering effect." The dilemma worsens over time as accommodations become habitual and/or harmful to self.

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Supportive communities may assume a variety of forms, but common features include members' mutual respect for human dignity, recognition of each participants' worth, permission to be expressive, authentic, and/or critically reflexive about the community or its constituents. Interactions in such communities are dominated by face-to-face encounters. Participants in supportive communities describe themselves as "members" or describe the community as "a place I belong." Connection to the community is revealed in these latter phrases, and also by voluntary investment of time and energy in communal activities. Participation in communal life is a key component of one's social identity.[p] Robert Nisbet's definition of community informs my application of the concept in this project:

> [Community] draws its psychological strength from levels of motivation deeper than those of mere interest ... Community is a fusion of feeling and thought, of tradition and commitment, of membership and volition ... Its archetype, both historically and symbolically, is the family, and in almost every type of genuine community the nomenclature of family is prominent (Nisbet 1966, 47-48).

For participants in this research project, childhood social vulnerability continued without resolution in the non-supportive, abusive atmosphere characterizing their early family or caretaking situations. Unrelieved social vulnerability prevented these individuals from attaining empowerment. In the course of this research project, I learned to conceptualize empowerment as one's ability to *implement* (rather than impose) a definition of situation or self that is satisfying, meaningful, and adaptable to many different social and personal contexts.

The essential features of these early situations denied

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empowerment to these individuals in two ways: the definition of their situation (i.e., a member of a family) and self (i.e., differentiated position in this family) were proffered in negative, demeaning ways; and these received definitions could not be altered by the individual, whose age-related social vulnerability precluded knowledge of alternatives to received definitions.

In essence, these primary socialization processes represent a symbolic loss of community: the family/community could not provide support nor lead to empowerment for the individual. Marked by unrelieved social vulnerability, these early experiences resulted in: need for definitions of situation/self that meaningfully explained their experiences and sense of self; a heightened susceptibility to others' offerings of definition; and a need for community.

As children and young adults, individuals accommodated these experiences of unrelieved social vulnerability in various ways (e.g., they developed a delusional world that was pleasant). Alternatively, attempts to accommodate their feelings of social vulnerability led to coping difficulties which drew the attention of others (e.g., they attempted suicide) or became an intolerable, personal burden (e.g., they were debilitated by feelings of anxiety or fear). Whether self or other-initiated, coping difficulties were brought to the attention of mental health professionals for redress.

Practices of mental health professionals, and treatment regimes recommended by them for consumers in their care, h

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unwittingly exacerbated felt social vulnerability and/or failed to relieve it. Frequently, treatment practices involved consumers in illusory communities (this idea is elaborated below), undermining their unarticulated need for an authentic and supportive community. Dominant treatment modalities used by practitioners, i.e., psychotherapy, psychiatric hospitalization, and major psychiatric drug administration, conflate problems of social vulnerability by communicating invidious definitions of situation (e.g., the consumer is "mentally ill" or a "mental patient") and self (the consumer _is_ "manic-depressive" or "schizophrenic"). Without capacity to alter or redefine the professionals' depiction of the situation (by virtue of their social vulnerability state), the need for definition that "explains" their coping difficulties impels an embrace of what is proffered. Hence, their primary self-identity becomes couched in terms of "mental patient."

Additionally, the need for community is unintentionally "assuaged" by assignment to a diagnostic category _and_ through hospitalization experiences. Both provide consumers' with membership in "pseudo-communities." Unrelieved social vulnerability propels an acceptance of reality constructions (e.g., professionals' communications) that offer diagnostic categories as the group in which particular consumers "belong," and the psychiatric hospital as a safe haven composed of similar peers and expert helpers. Specific practices of providers embodied in psychotherapy (e.g., sexism, racism, classism), and others manifested by hospital personnel during inpatient care experiences (e.g., discounting consumers' communications) may also add to the experience of social vulnerability. (Departures in standards of care by individual providers, however, sometimes prove beneficial to consumers.) Consumers' susceptibility to definitions offered is enhanced in total institutional settings, where physical and social control are predominantly in the hands of providers.

In contrast to consumers' experiences with professional mental health care are experiences at the consumer-run organization, Alternatives By Consumers (ABC). Many facets of organizational work, pursued by consumers differentiated by their level of involvement with ABC activities (e.g., staff, volunteers; "guests" only), attenuate the social vulnerability and consequent need for community that consumers experience.

Findings from this research indicate that an important marker for attenuation of social vulnerability is expressed by ABC consumers' embrace, rejection, or extent of ambivalence toward self-identity constructions specific to ABC that are posed in terms of "consumer advocate." The continuing experience of social vulnerability is marked by consumers' embrace of self-identity constructions posed in terms of "mental patient." These are not mutually exclusive categories; paradoxical and/or contradictory self-constructions (e.g., self is depicted as an "advocate" <u>and</u> "mental patient") reveal that attempts to resolve social vulnerability are underway.

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Organization of the Study

In the remainder of this study, I explore the ways in which social vulnerability accumulates in layers of experience for people who later become mental health consumers. I have organized this study so that each of its three parts contributes essential components needed for the final analysis.

Part I: Overview of Study. In this portion of the manuscript, I review relevant literature for this substantive area, i.e., literature that informs an understanding of mental health care experiences (Chapter 2). I turn next to an overview of methods and methodology that directed this project, and summarize the characteristics of the sample that was selected through application of my methods (Chapter 3).

Part II: Case Study. I begin the two chapter case study by examining the natural history of the Alternative By Consumers organization with special attention to sociohistorical context and its first champion and founder (Chapter 4). The second chapter of the case study is devoted to an examination of the chronological evolution of the organization. The discussion is framed by the application of a stage analysis model of "social problem-movements" to these data. I also explore the types of organizational work pursued by members and leaders of ABC, relating the effects of their work, and their import, on practice and policy in the traditional care system. In the conclusion of the chapter, I offer a theoretical critique of the model used (Chapter 5).

Part III (Volume II): Individual data analyses. Analysis of findings in this part of the dissertation are focused on

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personal information obtained from volunteers for the in-depth interviews. In the lead chapter of this part, I examine and analyze consumers' treatment experiences, noting the duration of their mental health care career and types of inpatient and outpatient treatments they have experienced (Chapter 6). Many treatment experiences are shared by consumers who become involved at ABC, but it is the transformation of this shared base of understanding into a genuine community that is next examined. I look with special interest at the social relationships that form in its setting and how those relationships affect the larger social world of ABC consumers (Chapter 7). I conclude Part III by compiling consumers' critiques of the care system, and of their own organization, ABC (Chapter 8).

Part IV: Conclusions of Study. In the final section, I outline in detail the grounded theory of mental health consumerism and the substantive general theory, which I have called "toward a theory of social vulnerability states," to indicate its nascent stature. These theories are derived from preceding analyses and integrated with support found in literature review, research studies, and extant theory (Chapter 9).

In the last chapter, I offer practice and policy recommendations in the context of the grounded theory of mental health consumerism, the substantive general theory of social vulnerability states, and other relevant theories and/or research studies that help illuminate the significant obstacles in attempts to transform the industry of mental health care. I conclude the study by highlighting the contribution ma

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made by the theories of mental health consumerism and social vulnerability states to the discipline of sociology, but especially to possibilities of social change (Chapter 10).

CHAPTER END NOTES

(a)I am using the term social problem in the manner outlined by William Faunce (1981). Faunce notes that the term social problem can apply to "any condition that is generally regarded in a society as requiring reform or change" (Faunce 1981, 8), and offers the following, widely accepted, definition: "A social problem is a situation believed to be a threat to or an infringement upon an established social value and considered capable of amelioration or elimination by appropriate social action. A social problem has the following elements: (1) a situation capable of measurement; (2) a value believed threatened thereby; and (3) a realization that the situation and the value may (theoretically) be reconciled by group action" (Merrill [1948] in Faunce 1981, 8).

Despite controversy over measurement of the incidence of conditions deemed to be "mental illness," enumeration of people labeled "mentally ill" in U.S. society are routinely conducted. Moreover, mental health is valued in this society, and there is wide-spread belief that "mental illness" is amenable to treatment by mental health professionals. Thus, situations researched in this study that preclude or stymie recovery of mental health can aptly be described as U.S. social problems.

(b)For a detailed discussion of deinstitutionalization policy history and practice, which focuses on political-economic factors, professionalist forces, institutional factors, and the role of popular forces in development of the practice, see Phil Brown, The Transfer of Care: Psychiatric Deinstitutionalization and its Aftermath (London: Routledge & Keagan Paul, 1985).

(c)For review of works that connect problems of U.S. homelessness to mental health practices, see e.g., Hombs and Snyder 1982; Hopper 1982; Halpern et al. 1980; Torrey 1989.

(d)The field notes from 1983 were collected during a course in field work methodology at Michigan State University (Sociology 955) taught by Dr. Barrie Thorne during the fall of that year. All written notes have been altered to insure anonymity for those observed. The director of the organization, and all people I

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observed, were informed of my purpose while field notes were being gathered and had the opportunity to give consent--or decline their consent-- for their participation in my study.

These field notes describe activities and conversations occurring at ABC's office site during my scheduled observation hours. Two in-depth interviews (for which informed consent was received), and notes taken at a public presentation of ABC's programs to a mental health task force also comprise part of the data from 1983.

The 1986 field notes also focus on in-house activities and conversations occurring at the ABC Center. I volunteered my help to ABC a minimum of one afternoon each week from June to mid-September, before being recruited for a paid position at the end of that month, which I accepted. Although I undertook this part of the field research on my own, I followed the same informed consent procedures used in 1983, and have altered compiled notes to protect the privacy of people patronizing or staffing the organization. Permission was secured from the Director of ABC before I started.

(e)I became interested in this organization through a field-methods course at Michigan State University in 1983, when I spent ten weeks as a participant-observer at their office site. I stayed in contact with the group and the director, Steven Ashton, over time. Ashton knew of my research interest in consumer-initiated mental health care. When he called in the fall of 1986 to offer a full-time position to me, as an Associate Director of the ABC "OUR Project," I accepted. I worked there nearly two years in that capacity. While emotionally exhausting, ABC work was also frequently exhilarating and inspiring. There were few "dull moments." I am grateful for the informed perspective this opportunity allowed.

(f)The institutional syndrome referred to here has been documented by Erving Goffman in <u>Asylums</u> (1962). He argues that a self-mortification process occurs when people are hospitalized in total institutions, such as mental hospitals. It is a process through which an individual's sense of self is disturbed.

> The whole experience of mental hospitalization promotes weakness and dependency. Not only are the lives of patients controlled, they are constantly told that the control is for their own good, which they are unable to see because of their mental illness. Patients become unable to trust their own judgment, become indecisive, overly submissive to authority, frightened of the outside world (Goffman, 1962).

Consumers' versions of this experience support Goffman's arguments:

> ...(A)fter my hospitalization, I was convinced of my own worthlessness. I had been told I could not exist outside an institution. I was terrified that people would find out I was an expatient and look down on me as much as I

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> had looked down on myself. For years I feared that any stress, any difficulty, would lead to my total collapse (Chamberlin 1978, 7).

(g)Feminist scholars have noted processes of sexism in numerous institutionalized practices in Western cultures. Selected works which have informed my research include: institutionalized sexism in religion and medicine (Daly 1978); sexism incorporated in world-views and bureaucracies (Ferguson 1980, 1983); sexism in mental health care (Chesler 1972); sexism in welfare state practices (Wineman 1984); sexism in psychological theories (Miller 1986 and Schaef 1985); sexism in the corporate world (Kanter 1977); sexism in language (Spender 1980); sexism in creation of patriarchy (Lerner 1986); sexism as political oppression (Frye 1983); sexism incorporated in societal formations (Rubin 1975).

(h)Although American Psychiatric Association members argue that schizophrenia should be understood as a chronic illness (excepting episodes of "illness" that last less than 6 months), an important dialogue has begun in psychiatry that challenges this notion.

Harding et al. (1987) has argued that "rather than uniformity, there is considerable heterogeneity in the long-term course of schizophrenia ... Recent longitudinal research suggests a much different picture involving recompensation, significant improvement and recovery as well as an occasional deteriorating course" (1987, 477). Her work provides an important challenge to the dominant conceptualization of schizophrenia in psychiatry, which heretofore has largely been challenged only outside the ranks of psychiatry (e.g., by psychoanalytic psychologists [Karon and VandenBos 1981] and sociologists [Hill 1983; Farris and Dunham 1939]).

(i)See Baxter and Hopper, "Shelter and Housing for the Homeless Mentally Ill," (pp. 109-140) in Richard Lamb (ed.) <u>The Homeless Mentally Ill: A Task Force Report of the American Psychiatric Association</u>. (Washington, D.C.: American Psychiatric Association), 1984. Baxter and Hopper review programs in New York City serving the homeless, the data base used to assess numbers of homeless people, and relevant U.S. policy, practices, and advocacy strategies for this sector of the population.

(j)See e.g., Evelyn Fox Keller, "Feminism as an Analytical Tool for the Study of Science," *Academe* (September-October), 1983: 15-21, for an excellent discussion of sexist bias in "normal science."

(k)"Insofar as psychological theories are elements of the social definition of reality, their reality-generating capacity is a characteristic they share with other legitimating theories; however, their realizing potency is particularly great because it is actualized by emotionally-charged processes of identity-formation. ...Its internalization is accelerated by the fact that it pertains to internal reality, so that the individual realizes it in the very act of internalizing it" (Berger and Luckmann

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1967, 178.

(l)Mentalism can be described in its simplest form as an unreasonable fear of "mental patients" (Chamberlin 1978, 196). This simplistic definition, however, belies the intrapsychic damage that occurs when this belief is internalized by consumers and non-consumers alike.

> What do we mean when we call a person "sick" because we don't like his or her behavior? We don't really mean that the person is suffering from an illness; it's an easy way to discredit or dismiss that person's ideas or actions, a way not to listen to what he or she is saying. It's a way of turning the problem over to the experts--the psychiatrists--even though we know that we wouldn't want that to happen to us. We use words that sound clean and sterile, "mental illness" and "mental hospital" when we know we mean "crazy" and "snake pit" and "booby hatch." We draw away from anyone we know is a mental patient, and we draw away from the unknown and mysterious areas within ourselves. Mentalism cripples us all (Chamberlin 1978, 218).

(m)Throughout this project, I embrace the understanding that reality is socially constructed, or more accurately, multiple social realities are constructed by social actors in differentiated social positions within a given society. My understanding of these issues rests largely on the work of Peter Berger and Thomas Luckmann, The Social Construction of Reality: A Treatise in the Sociology of Knowledge (Garden City, New York: Anchor Books), 1967. Their premise is that "reality is socially constructed and ... the sociology of knowledge must analyze the processes in which this occurs" (p.1). Much of this project has been devoted to this interpretive task.

(n)"Bracketing the natural attitude" refers to a phenomenological concept which involves suspending our "everyday" belief, for the purposes of examining essential qualities of phenomena. The natural attitude "is the pervasive unquestioned assumption that our everyday surroundings are real and provide the same reality for others ... it pervades all mental processes which are directed toward [apprehension of] the world" (Jennings 1986, 1237). (These issues are more thoroughly explored in Chapter 3.)

The "life-world," or *Lebenswelt* is a concept developed by Husserl and examined in Rogers (1983). It refers to "the surrounding world that provides the grounds of conscious existence ... Thus the life-world is the 'world in which we are always already living.' Yet phenomenologists also attend to the culturally specific features of any actual life-world that instantiates the universal forms of lived experience. They recognize that the life-world, like consciousness and constitution, is a unity in multiplicity" (Rogers 1983, p. 49,50,51). I apply this term particularly in this latter conceptualization; it is similar to, but not subsumed by, concepts of multiple [socially constructed] realities applied by sociology of knowledge theorists.

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(o)This is a partial quote from a 1983 interview I held with Steven Ashton, founder of Alternatives By Consumers. He was responding to a question about effects of institutionalization for consumers, and noted: "We're the most vulnerable population there is: we're controlled by society; we're controlled by drugs; and it's so hard to take charge of one's life after that."

(p)This insight is derived from a statement of John Dewey,in <u>The Public and its Problems</u> (New York: Holt, 1927), p. 216: "Unless local communal life can be restored, the public cannot adequately resolve its most urgent problem: to find and identify itself."

PART I

Overview of Study

Chapter 2 - Review of the Literature

Chapter 3 - Methods and Methodology

CHAPTER 2

REVIEW OF THE LITERATURE

Introduction

Literature that focuses on the mental health consumer experience, treatments, and consumer movements to provide services to their peers in the care system, can be characterized in four ways. Some works describe consumer experiences without consulting consumers (reviewed in section 1); some works rely on consumers' feed-back, but use it for instrumental (non-consumer benefit) ends (reviewed in section 2); some literature offers insight into the consumers' experience but fails to make connections to the dynamics of the political economy (reviewed in section 3); and a small number of authors connect authentic consumer experience to the workings of larger social structures (reviewed in section 4). Other existing literature is important to understanding the mental health consumer experience, but is rarely applied to consumer-focused analyses (reviewed in section 5).

Although these divisions are not rigid, characterizing the literature in this way provides a quick referencing of the part each category plays in building the synthesis between perspectives most important to this project. While this is not an exhaustive review of all materials that could conceivably apply to a mental health consumer-focused project such as this, it provides a useful map of the "as is" mental health care system (section 1), the distortion in research which helps maintain that system (section 2), some of the additional areas requiring attention if system change is an end-goal (section 3), the larger context within which change would occur (section 4), and a glimpse into changing practices--and conceptualizations of the issues--which have already begun (section 5).

Section 1: Literature Lacking Consumer Voices

The first category includes literature that depicts the experiences of mental health care consumers (American Journal of Psychiatry 1980; Eckholm 1986; Mechanic 1978; Ubell 1986; Ahmed and Plog 1976; Freeman and Simmons 1963; Krauss and Slavinsky 1982; Rosenstein and Bass 1979), their "careers" as "mental patients" (Lamb 1976; Brearley 1982; Burgess and Lazare 1976; Rowan 1980; Test 1981; Scheff 1966; Roman and Trice 1974; Scull 1977; Estroff 1981b) and/or recommends policies and treatment practices based on observations of consumers in the care system (Alvarez 1976; Bachrach 1983a, 1983b; Barofsky and Budson 1983; Greer and Greer 1984; Bassuk and Gerson 1978; Brown 1985; Talbott 1984; Warner 1985; Williams et al. 1981; U.S. Office of Research, Statistics and International Policy 1974; Caton 1984). These researchers have observed consumers in hospitals and programs and construct case histories from hospital records, but they have not talked to consumers themselves. The common characteristic in these works is an inattention to micro level realities, or a lack of consumer voices.

These works do contribute an important understanding of the situations that consumers face, but they do not reflect the realized experiences of mental health consumers. Inpatient or outpatient programs do not empower consumers when they are designed by professionals who rely on assumptions about "mental patients" and do not acknowledge the degraded status of consumers in community situations. When programs are designed that do not anticipate personal growth or healing will occur, professionals unwittingly communicate expectations of continuing powerlessness to consumers. This process is especially harmful to consumers with diagnostic labels suggesting "severe" and/or "chronic mental illness."

> To effect the most desirable clinical outcome...the chronic mental patient requires long-term care from the mental health delivery system, which includes the following: 1. Drug therapy.... 2. Crisis intervention to stabilize episodes of psychosis.... 3. An extended duration of full or partial hospitalization or outpatient care.... 4. Housing alternatives if the patient is unable to live independently... (Caton 1984, 159).

The assumptions in the presentation of needs for a "chronic mental patient" above reveal expectations: drugs are a necessary therapy; crises will occur during which persons involved become psychotic; hospitalization needs will continue; and independent living may not be possible. While this direct terminology is not used by Caton, the tacit expectations of continuing inabilities to cope in community settings is nonetheless embodied in this treatment plan. For many consumers, such treatment plans are perceived as a definition of their own situation. As such, they may appear to consumers as a prophesy of their own future. When such constructions occur, they become the "incurable," "chronic" "mental patient" their doctors told them they were.

For other consumers, similar communications are received from professionals operating the "rehabilitation" programs they are frequently forced to attend. "Job skills" programs that offer advice and/or training only in secondary market jobs tell consumers about the futures they can hope to have.[a]

A good example of this first literature category is provided by Talbott (1984) in his edited compilation of research studies, The Chronic Mental Patient: Five Years Later. Despite his citation of authors who pose serious challenge to the notion of chronicity in schizophrenia and other "mental illness" usually labeled chronic (e.g., manic-depression; borderline personality), Talbott offers this summary statement in his introduction:

> The progress we have made in the last five years is impressive, not only in the amount of information, but in the correction of widely held beliefs. We know, for instance, that schizophrenics do relapse, despite the best care, and the causes of relapse are symptomatic, not institutional....The task of the next five years will be to translate this knowledge into action, to make our certain knowledge work (Talbott 1984, 3).

Some mental health care planners incorporate this baseline assumption that schizophrenics will relapse in program design. This expectation is subtly communicated to consumers involved in such programs through the type of activities included (e.g., washing windows or dishes) and excluded (e.g., computer word processing or programing training). It is also communicated by segregating consumers in the programs by their diagnoses, and lowering the level of expected skill attainment for groups deemed to be "chronically mentally ill" (e.g., schizophrenics).

Since part of the institutional syndrome that psychiatric patients display is obsequious behavior towards those in authority, affected consumers meet these tacit expectations and suffer relapse. They escape the "infantilizing" and "humiliating" programs (Rose and Black 1985, 103) by returning to the hospital, where demands are few and their decisions about their future are left to others.[b]

Because those in authority believe that relapse is inevitable, treatment regimes also manifest these expectations. This results in mental health care professionals' dependence on certain "maintenance treatments," such as medication with neuroleptic drugs or electroconvulsive "therapy" (ECT). Inattention to the micro realities of consumers' experience with such treatments and ignorance of community living situations which may exacerbate individual coping difficulties perpetuate some professionals' belief that such treatments are indicated.

> Among the most tangible benefits of educational strategies is the increase in patient compliance and cooperation with treatment. An informed patient with an appreciation of the rationale for treatment is more inclined to accept it. ... [One strategy being investigated] ... places heavy emphasis on teaching patients to recognize early signs of impending relapse so that medication can be reinstituted and the psychotic episode aborted (Heinrichs 1984, 126).

When research on the effects of these treatments also embodies assumptions about the consumers involved (as illustrated by the next category of works), then a wide array of "scientific" research can be used to legitimize the dominant view of appropriate services and/or treatment.

Another example of this approach affects the social understanding of the mental health care system. This view incorporates assumptions about persons seeking treatment from the system. In Greer and Greer's article, "The continuity of moral reform: Community mental health centers" (1984, 397-404), such assumptions are apparent. The premise of their article is found in a summary statement:

> Community Mental Health Centers [CMHCs] represent the latest phase of the movement to create and maintain a moral order which includes the mentally handicapped against the brute competition of markets. American society has wavered between the two poles from its beginnings. Today CMHCs ... successes indicate the will and capacity to extend humane care to the mentally ill (Greer and Greer 1984, 404-5).

More than twenty years after the inception of the CMHC network, the authors are able to make this claim largely because their research excluded <u>any</u> contact with consumers of CMHC services. To assess successful centers, the authors spoke with "its [Community Mental Health Center] board members, its professional staff, its cooperating agencies in the locale, its friends and its enemies" (1984, 399). Successful CMHCs were "dispensing services as board-governed bodies and [complying] with the regulations concerning representativeness" [as set forth in the 1963 law creating the CMHC network] (1984, 399). Thus, the criteria for success was determined by interviewing professionals and staff who could authoritatively comment on the work of the CMHC governing board and how closely they followed federal requirements. Notably absent was any research into the quality or effectiveness of services provided by these successful centers; contact with consumers knowledgeable about the actual services being provided was not sought. Assessing the CMHCs <u>treatment services</u> was not part of the research design. The information provided by those developing and operating the programs lead these researchers to conclude that humane care was being successfully delivered.

In another section of the article, it becomes clear why mental health consumers were not consulted. The authors rhetorically ask what has intervened to improve the lives and status of the [people labeled] "mentally ill". They answer their question in this way:

> In general, one can discount 'self help.' Their maladies disable most mental patients socially, if not practically, from organization and leadership (Greer and Greer 1984, 397).

Greer and Greer can exclude consumers as legitimate informants for their research because they are disabled. Self-help efforts that may have been in operation at the various Centers studied can be discounted because their effect is assumed to be negligible. The CMHC professional-employee and/or board member is the (only) legitimate source for defined success of the Centers.

Another section of their article illuminates the ways in which literature that distorts consumer experience simultaneously maintains the system. They note that the mental hygiene movement in the U.S., founded by Clifford Beers, ushered in a new era of attention to people labeled "mentally ill" (Greer and Greer 1984, 396). They fail to note that Beers was an expatient whose early advocacy efforts for and with other patients led to the later involvement of professionals in the movement.[c] This oversight allows their previous typification of mental patients as socially and practically disabled (cited above) to stand. The irony is complete when other facts about Beers are juxtaposed to their thesis.

Beers recovered at "The Retreat," an asylum established by Quakers (i.e., the Society of Friends) in the 1800s to provide "a calm, nonstressful, positive environment, known as moral treatment" (Mauss 1975, 332). Since the thesis of the Greer and Greer article is that CMHCs have provided continuity in "moral" treatment, their exclusion of consumers from research procedures and the disavowal of a societal debt owed to a consumer who benefited from "moral treatment" and worked to provide similar treatment for others (i.e., a self-help effort), weakens the legitimacy of their claim as it reifies the goodness of CMHCs.

Research such as this allows the contemporary mental health care system to be lauded in its present day form, <u>and</u> allows continuing (research-sanctioned) stigma toward consumers of the CMHC services. Opportunities to confront the issue of stigma which the Greers note as a problem ("the mentally ill in America ... are still the most stigmatized of populations" ... 1984, 397), afforded by their citation of Beers' contributions, are eschewed.

Implementation of their unwittingly biased research design led Greer and Greer to conclusions that ignore the consumer experience. Inattention to the realities of consumers' situations and lack of consumers' voices in their research design contributed to the judgment that the CMHCs studied were successful. Community Mental Health Centers were funded to provide effective mental health care services to consumers; but the quality of care provided by these successful centers remains unknown. The establishment view of the system, however, is well represented by CMHC professionals and Board members who evaluate their own work.

Section 2: In Spite of Consumer Voices

In the second category are works that *do* consult consumers' and observe them, but distort the consumers' meanings or intentions in order to propose theories about mental illness or policy/practice recommendations (Alexopoulous 1979; American Journal of Psychiatry 1980; Estroff 1981a; Somer and Osmond 1984; Singh 1976; U.S. Congress 1979; Van Putten 1974). This group of works also includes literature that ignores consumer input and/or uses research known to be questionable to justify theories about "mental illness" or specific diagnoses (e.g., Harvard Medical School Mental Health Letter 1987; Torrey 1989). Overall, this grouping can be characterized as works produced *in spite of consumer voices.* This literature is important to this project because it depicts the actual processes involved in the majority of policy, program, and treatment practices. It overlaps with the first category reviewed for this reason, but the analytical emphasis here is on portraying the "as is" or normative nature of the care system. However, the element of distortion in this literature category serves the system and its practitioners rather than the consumers. Professional bias incorporated in research assumptions overrides concerns that would surface were consumer input evaluated without an overlay of "mentalism."

Peter Breggin (1983) cites an example of this second category. He has advanced the theory that the most potent psychiatric drugs exhibit their therapeutic effect through brain-disabling actions rather than through any amelioration of psychiatric disorders. Breggin reviews the research findings of hundreds of psychiatric inpatient studies and suggests that "in most studies one must read between the lines to obtain data concerning the disastrous subjective effects of treatment" (Breggin 1983, 36).

One study that Breggin (1983, 36-38) examines exemplifies the works that I include in this second literature category. Dr. Singh (1976) attempted to correlate what he called "dysphoric responses" [i.e., mental anguish] to use of major tranquilizers and/or a placebo, or a combination of these substances with an antiparkinsonism agent, with "failures to improve" in a double-blind study. Singh found that 61% had "dysphoric responses" to one or both of the drugs. These responses included an _increase_ in one or more of the following: "depression, anxiety, ideas of guilt and suicidal ideas." Forty-four percent were considered serious and followed a discernible pattern described by Singh in this way:

> They complained, often repetitiously and sometimes belligerently, that the treatment was making them worse and that they were much better before the start of treatment. Their social functioning, after initial improvement, seemed to progress no further, and they continued to voice many of their previous delusions and to experience hallucinations and ideas of passivity and influence. From time to time some of them became quite upset, repeatedly and even belligerently demanding attention or a discontinuation of treatment (in Breggin 1983, 37).

Breggin offers this interpretation of the research:

> Singh's language discredits the patients. The patients' reaction to being subjected to brain dysfunction against their will is called "ideas of passivity and influence." Singh further attributes the anguish to primitive impulses and other psychological mechanisms, rather than to genuine upset over the severe mental dysfunction produced by the treatment. Wholly justifiable resentment is called "belligerence."....He believes that these reactions are not wholly explicable as reactions to the severe side effects of the drugs, but he can find no suitable explanation for them other than to assume some special form of schizophrenia in these patients (Breggin 1983, 37).

Breggin shows that many researchers assume consumers cannot be trusted to evaluate treatments they are subjected to because of their "mental illness," which renders their judgment invalid. Such research perpetuates the status quo of the mental health treatment system. It assumes that consumers are not trustworthy respondents, and offers no challenge to the prescribed "usual and customary" treatments for mental disorders.

Research produced "in spite of consumer voices" is most damaging to those diagnosed with mental "diseases" that are deemed severe (e.g., schizophrenia, manic-depression). It is exacerbated by an historical trend that builds on constructs which were originally flawed and are subsequently used as a "da

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"data base" to defend medicalization of the concept.

The best example of this trend is examined by Lewontin, Rose and Kamin (1984) who explore the "clash of determinisms" in schizophrenia (1984, 197-232). They first review research that relies on the notion that schizophrenia is a molecular disorder of some kind (e.g., in serotonin metabolism, noradrenaline metabolism, dopamine metabolism, acetylcholine metabolism, endorphin metabolism and prostagladin metabolism) that interferes with the messages between brain cells, resulting in scrambled information processing and inappropriate responses for persons labeled schizophrenic. Of this body of research, Lewontin et al. note:

> Rarely have results obtained by one group of researchers been confirmed by another group of researchers in a different group of patients. Rarely has any resolution of conflicting claims been attempted. Rarely has any concern been expressed by the enthusiastic clinical researchers that schizophrenia might be associated with many different biochemical effects, or indeed that many different types of biochecmical change might lead to or be generated by the same behavioral outcomes... (Lewontin et al. 1984, 206).

Noting the unverifiable biochemical theories deemed to explain the onset of schizophrenia, the authors focus on the ideology of biological determinism. This insists that "biological events are ontologically prior to and cause the behavioral or existential events," and that the underlying altered biochemistry "must be some type of genetic predisposition to the disorder" (Lewontin et al. 1984, 206).

> The lineage of the effort to find genetic predispositions runs back through the eugenic thinking of the 1930s and 1920s, with its belief in genes for criminal degeneracy, sexual profligacy, alcoholism, and every other type of activity disapproved of by bourgeois society. Only thus can we account for the extraordinary repetitive persever-

> ance and uncritical nature of research into genetics of schizophrenia (Lewontin et al. 1984, 207).

Lewontin, Rose and Kamin examine the research done by the late Franz Kallman (1938), "the most influential psychiatric geneticist in the English-speaking world." It reveals that his genetic research on schizophrenic twins is characterized by "arbitrary corrections" to his data findings; "ambiguous" and/or "contaminated diagnoses," and "virtually no infor mation ... about procedures employed in his study." And yet, Kallman's "figures are presented to students in today's textbooks as the fruits of the impartial science" (Lewontin et al. 1984, 210-11). Their summary perspective on Kallman indicates the far-reaching ideological effect of early pursuits in "normal science." This continues to affect psychiatric and medical ideologies which defend popular perceptions of schizophrenia:

> Perhaps the chief harm brought about by Kallman's deluge of incredible and poorly documented data was to create a climate in which the findings of subsequent workers seemed so reasonable and moderate that they escaped serious critical scrutiny. Thus, Kallman's data have [partially] faded from the body of acceptable evidence, but the belief for which he was largely responsible--that a genetic basis for schizophrenia has been clearly established--still remains powerful in and out of science (Lewontin et al. 1984 212-213).

Their latter supposition is clearly seen in contemporary research. One example reveals how strongly entrenched the biological explanations of the disorder are. It is provided by E. Fuller Torrey, who has authored 10 books in clinical and research psychiatry and has appeared on the CBS (Columbia Broadcasting System) network newsmagazine feature, "60 Minutes" (August, 1986) as an authority on schizophrenia. The following quote from one of his articles was also used during the TV broadcast:

> Schizophrenia and manic-depressive psychoses ... are chronic diseases of the brain, in the same category as multiple sclerosis, Parkinson's disease, and Alzheimer's disease .... (Torrey 1989, 10).

In his written work, Torrey notes that "the causes of the disease(s) are still unknown..." (e.g., Torrey 1989, 10), but the sole explanation offered links the condition to the presence of brain disease. In his TV appearance, no attempt was made to portray the ailment as anything other than a brain disease. Millions of TV viewers watching "60 Minutes" were not informed that competing theories or evidence refuting Torrey's claims existed. Television reporters and/or editors for "60 Minutes" did not challenge his view that schizophrenia is a genetically transmitted brain disease. Thus, voluminous literature and wide exposure through the mass media lends credence to this ideology of biological determinism. As this tendency continues, ideological knowledge cited by such experts enters the social stock of knowledge used by <u>another</u> generation to explain the phenomena of "mental illness" and/or its specific diagnostic representatives (e.g., "schizophrenics," "manic-depressives"). This helps to legitimize medical treatments.

It is no coincidence that present day biological investigations into causes of severe "mental illness" stem from work of eugenicists involved in "purifying" Germany for the Nazis. Nor is it happenstance that biological determinist theories are again coming into favor:

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> embraced as self-confirming by all who prefer and defend the status quo and welcome its legitimation by science (Bleier 1984, 9).

The New Federalism inaugurated with the first Reagan administration shares an understanding of social processes posed in biological givens,[d] albeit one step removed from the "reactionary political applications" (Bleier 1984, 9) used by the Nazis.[e]

While issues of biological determinism have captured the critical attention of feminist scholars (e.g., Bleier 1984), its advance remains virtually unchecked in areas most specific to mental health consumerism. One indication which promises to affect the operations of "normal science" in mental health for many years to come is the emphasis on funding genetic and/or biochemical theories for "mental illness" that the National Institute of Mental Health (NIMH) has advanced during the 1980s:

> NIMH research and training funds, which were central to community orientations, have been drastically curtailed, and funding now emphasizes biochemical modes. Psychology and psychiatry therefore are unable to support graduate and professional training in social psychiatry, thus cutting off that option for many practitioners. Research in mental illness, particularly in the psychoses, has gone in a more biochemical direction, since both physician and non-physician researchers consider chemical intervention to be more reliable than other treatments (Brown 1985, 150).

Section 3: Inattention to Macro Realities

The third category is literature produced by consumers, advocates (professional and lay) for consumers, academic researchers and/or practitioners. This class of works can be characterized by careful attention to consumers' experiences, opinions and recommendations for policy and practice in the mental health field (Barnes and Berke 1973; Beers 1953; Benzinger 1969; Briggs 1975; Clark 1975; Frank 1976; Gotkin and Gotkin 1975; Green 1964; Margolis 1973; Walker 1976; Wing and Brown 1970; Goffman 1962, 1959; Hirsh et al. 1974; Lamb 1984). These works can be characterized by _inattention to macro level realities._ Connections between group or individual consumer situations and larger structural conditions are not seen and/or not addressed. Material conditions that impinge on consumers (or consumer-run organizations) are not adequately analyzed. While these works contribute insights to discourse in the field, the limited vision they exemplify must be addressed if reform or transformation of the care system is a goal.

Erving Goffman's _Asylums: Essays on the Social Situation of Mental Patients and Other Inmates_ (1962), is an example in this category. His book offers the contextual richness of ethnographic research in psychiatric hospitals. Using theories of symbolic interactionism, Goffman illuminates processes involved in the "institutional syndrome" (i.e., the self-mortifying patterns of behavior that inpatients and expatients of psychiatric institutions manifest). However, as an interactionist, Goffman does not discuss the larger structural issues that contribute to a person's acquisition of the label "mental patient." This perspective obscures the structural dimensions that maintain an individual's status as "mental patient" and/or as "chronically mentally ill." Did the individual come to the psychiatric institution from a low socioeconomic family of origin or from the middle or upper classes? What level of education did the individual attain before incarceration in the hospital? What is the unemployment rate in the society to which the individual will return? Is there a labor shortage that unskilled and semi-skilled laborers can fill, so that hospitalized working class people can return to paying jobs and be valued for their contributions? These are just some of the questions, and dynamics, that cannot be seen when the focus is narrowly set or confined to one perspective.

Works which examine individual experiences of conditions labeled "mental illness" and subsequent restoration of mental health are important to increase social understanding about conditions of hospitalization and social vulnerability. One former "mental patient" provides insightful commentary that illustrates this:

> What subdued us even more effectively [than psychiatric drugs] was mindless routine and our mindless participation in it. By treating us routinely as if we lacked the ability to make any choices for ourselves at all, little by little they persuaded us it was true. Subjected to a routinized disrespect and indifference, we began to believe something must indeed be wrong with us, something fundamental must be missing. We began to behave like the empty beings we were supposed to be (Brandt 1975, 168).

In this passage, the damaging effects of hospital practice become salient. While it is important to identify these processes, the focus on individual experience lends credence to popular conceptions that conditions labeled "mental illness" are private troubles. Such works provide scant commentary on macro social forces affecting individual situations. In the next section, I review works that deal with these macro and micro level realities.

Section 4: Exceptions, Situating Consumers

The fourth group of works can be characterized as "exceptions to the general rules" followed by previously reviewed scholars. They are works that acknowledge consumers' experiences and make connections to material and/or ideological conditions operating on macro levels (Belle 1982; Bernardez 1985; Rose and Black 1985; Breggin 1983; Chesler 1972; Harding 1986; Hill 1983; Magaro et al. 1978; Lewontin, Rose and Kamin 1984; Chamberlin 1978; Karon 1986).

To some extent, these works overlap with previous categories. As I noted in the introduction to this chapter, my primary intention in this review has not been to demarcate discrete categories of literature. However, the analytical distinction I want to emphasize in this category is the important connections revealed through authors' incorporation of consumers' voices in their approach to practice and/or research. Their importance to future directions in the mental health care field cannot be overstated.

If social change in mental health care is a valued criterion (as it is to consumers involved in the organization for this research project), then a comprehensive approach to study in this area is necessary. Contemporary mental health care involves structured inequalities between providers and consumers. The workings of the mental health industry are tied to economic, political, and ideological underpinnings. To relate these factors to the experience of mental health consumerism advances the interest of social change by expanding the information base on which it is predicated.

Also important in this category are works by practitioners/researchers who exhibit a sensitivity to personal and interactional factors affecting treatment issues and can relate them to sociohistorical or sociocultural conditions. Bertram Karon (1986), a practitioner-researcher, offers an historically based view of psychotherapy with people diagnosed as schizophrenics that informs present day practices:

> It is ordinarily believed that if a treatment is more helpful than its alternatives, it will be used. Yet, an early psychologically based treatment for schizophrenics [in the 1800s]--moral treatment--was tried out, found to be helpful, then abandoned. ... There has never been a lack of treatments which do more harm than good. They have in common that they do not require understanding the human condition. ...In our time, psychoanalytic psychotherapy, and other psychological treatment modalities (all of which involve listening to and trying to understand the patient) for schizophrenia are not fashionable; not because they are not helpful, but because they make the professionals who become psychotherapists, as well as the public at large, so uncomfortable. ... To understand schizophrenics is to perceive painful facts about the human condition that we would rather not know (Karon 1986, 2, 35).

Karon examines the history of treatments that have worked and been abandoned (i.e., "moral treatment"[f] which involved no punishment or physical invasion of the body), and looks at current treatments which continue (e.g., lobotomy, electroconvulsive therapy [ECT], psychiatric medications). These practices uphold his thesis that psychotherapists who have tried to understand people diagnosed as schizophrenic have succeeded; practitioners using treatments which do not require any understanding of the person involved have been ineffective.[1] Thus, Karon believes that emotional discomfiture is fundamental to understanding why people diagnosed as schizophrenic are shunned by professionals and the public, why they receive the treatments they do, and why these treatments are favored by practitioners.

Hochschild (1983) also relates emotional discomfiture to social processes, but focuses on its relation to research practices and theory development in the discipline. Hochschild (1983, 201) notes that some theorists deny that emotion is a tenable concept; others either ignore emotions or subsume it under other categories. But the importance of the concept, and its applicability to the issues, is not to be underestimated.

> What is emotion? Emotion, I suggest, is a biologically given sense, our most important one. Like other senses ... it is a means by which we know about our relation to the world, and it is therefore crucial for the survival of human beings in group life. Emotion is unique among the senses, however, because it is related not only to an orientation toward *action,* but also to an orientation toward *cognition* ... [e.g.,] When an emotion signals a message of danger or safety to us, it involves a reality newly grasped *on the template of prior expectations* (emphasis in the original) (Hochschild 1983, 219, 221).

Thus, Hochschild illuminates the import of the dynamics that Karon alluded to earlier. The emotional barriers to understanding people labeled schizophrenic orient action (e.g., treatment practices), cognition (e.g., myths about "mental patients" or "schizophrenics"), and expectations about

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[1] "So desperate have professionals been not to have to listen and understand, that nearly every physical system in the body has been claimed to be the cause of schizophrenia. The claims never replicate, and they never last more than five years" (Karon 1986, 16).

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the quality of interaction that can be experienced in their presence (e.g., it will be uncomfortable or dangerous). These actions, cognitions, and expectations can be seen in the historical and contemporary practices of the mental health professions (as detailed by e.g., Karon 1986; Grob 1983; Talbott 1984; Magaro 1976). This suggests that the emotional features of treatment for or with people deemed "severely mentally ill" augment the political, economic, and ideological forces that allow continuation of system practices in their "as is" form.

Expatients who have provided leadership for the 'mental patient liberation movement,' such as Judi Chamberlin (1978), confront the emotional barriers (noted by Karon (1986) above) in their attempts to change the system of mental health care as much as they confront economic, political and ideological forces which maintain the system:

> Many people--including expatients--are doubtful of our ability to help ourselves or one another. Mental health professionals are even more skeptical. ... We have been thought of as ... subhuman monsters or ... pathetic cripples ... (Chamberlin 1978, xi).

But the advent of the mental health consumer movement has initiated a change of perspective:

> In this decade, with the growth and emergence of the mental patients' liberation movement, we expatients have begun to shake off this distorted image and to see ourselves for what we are--a diverse group of people, with strengths and weaknesses, abilities and needs, and ideas of our own. Our ideas ... differ drastically from those of mental health professionals (Chamberlin 1978, xi).

Expatients participating in the movement channel their own emotions into avenues of change, developing alternatives to tra

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to traditional mental health care. "Many expatients are angry, and our anger stems from ...what we have seen and experienced" (Chamberlin 1978, xiv):

> Out of this anger has come action--working to change commitment laws, to inform patients about their legal rights, to increase Constitutional guarantees to patients, to end the demeaning and harmful psychiatric system and replace it with true asylums... voluntary, small, responsive to their own communities and to their residents--places to which people can retreat to deal with the pain of their existence (Chamberlin 1978, 7).

Some consumer groups, like the Alternatives By Consumers organization that my research focuses on, augment system offerings by providing auxiliary services and social support to consumers of the public mental health system. In contrast, other groups like the "Mental Patients' Association" founded by Chamberlin, seek to develop alternative treatments themselves--ways of helping others through emotional crises or dilemmas that do not involve structured asymmetry nor attribution of expert status to one party of the interaction and inferior to the other in the ways typical of treatment within the system. "Power," Chamberlin notes, "not illness or treatment, is what the system is all about. It is a power not usually spoken about. (Patients who do are often labeled paranoid.)" (Chamberlin 1978, xiii). She identifies racism, sexism and mentalism as beliefs which must be eliminated in the society and the system of care.

In my literature research, Chamberlin's work represents the most developed expatient perspective on the micro <u>and</u> macro realities that complicate and/or thwart patient-controlled alternative treatment development. And yet, the perspective of expatients can be enhanced by interdisciplinary scholars who enlarge this perspective by inclusion of still wider views--and targets for change (e.g., classism, professionalism).

Exemplary in this category of literature is David Hill's The Politics of Schizophrenia (1983). Hill offers three major criticisms of the mental health care system. First, he decries the use of diagnostic constructs for which there is little or no scientific basis; secondly, he documents the political bias (i.e., classism, racism and sexism) in the diagnostic process for people seeking or incarcerated for psychiatric treatment; and finally, he documents the extensive use of what he terms "punitive brain-damaging treatments" (i.e., over-use of psychotropic medications; electroconvulsive therapy [ECT]; and psychosurgery).

Using interviews and psychotherapy case studies, Hill links the contemporary mental health system to processes of social control. He amasses historical documentation spanning 400 years which show that the treatment of individuals considered mad has almost invariably been punitive and that the social control involved has usually been well disguised as benevolent concern for the victim. He argues that the various rationalizations used by mental health care professionals to camouflage the oppression involved have varied according to the socio-political world-view of particular cultures. Scrutinizing the political economy of the U.S., he also highlights the barriers to change (economic, ideological, and psychological) that must be addressed through advocacy efforts by con-

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sumers and others interested in changing the material and interpersonal dynamics involved in the practices of the mental health care system. Clearly, Hill not only believes that consumers are trustworthy respondents, but also that the struggles they face as they recover from their "mental illness" go beyond the immediate concerns in their home communities and connect to the larger realities of the political economy.

Section 5: Providing Context

In this final category of literature, I review literature that is helpful in conceptualizing the individual coping difficulties and collective care experiences of persons receiving mental health treatment. The vantage point of these works is not on mental health consumers per se, but they illuminate the effects of pervasive social processes on their situations. I examine and identify these processes in the following discussion.

In *Self, Society and Womankind: The Dialectic of Liberation* (1980), Kathy Ferguson explores necessary components of a theory of liberation. She asserts that: "Freedom and compassion are the elements of the liberation dialectic, and they involve defining one's own situation and taking the perspective of the other" (Ferguson 1980, 159). Her thesis depends on the conception of self offered by George Herbert Mead (1934), which "modified by a consideration of power and liberation, offers insight into the general issue of women's role in society" (Ferguson 1980, 153).

I believe that Ferguson's analysis of Mead and the construction of her theory of liberation apply to the situation of persons who are socially devalued in this society. This is not to assert that a literal congruence exists between categories of people socially devalued. However, the institutionalized processes which contribute to processes of social degradation (e.g., racism, sexism, classism) have been widely recognized in the discipline of sociology as sharing elements of process in common. The social position of another category of devalued people, mental health consumers, can thus be illuminated by attending to social patterns which are identified as integral to the social construction of women's situation.

Ferguson's analysis proceeds from Mead's (1934) thesis, that self formation depends on acquisition of "the composite of accepted social norms, rules and roles that Mead calls the generalized other" (Ferguson 1980, 154) which are given meaning and content through interaction with other selves. Human behavioral or personality traits are not innate; they develop in social interaction.

> Therefore, all arguments that justify and account for women's role in society by reference to their "nature," or to some set of innate character traits can be rejected. If all meaning and structure in the world are human creations, the result of human beings placing certain evaluations, judgments, and interpretations onto material phenomena, it must be concluded that women's role has been created, not ordained. The Meadian perspective ... requires that we look to our social structures and interactions to account for women's situation (Ferguson 1980, 154).

This conceptualization illuminates the manner in which

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social situations can be created. If it is possible to apply this understanding to a constructed situation for women, it may also illuminate ways in which the demeaned position of people labeled "mentally ill" has been created. If this argument is augmented by attention to ways in which social structural forces perpetuate such constructions, practices which maintain degraded social positions may be identified. This may increase knowledge of the ways in which macro social forces affect individual experiences.

Anthony Giddens (1983) suggests that social structure may be best conceptualized as rules and resources, organized as properties of a social system constituted by reproduced social practices (Giddens 1983, 66ff). "Rules generate--or are the medium of production and reproduction of--practices" (Giddens 1983, 67). Thus, "rules" which generate women's roles may be similar to those generating "mental patient's roles." Such "rules" (or role prescriptions, in Giddens' [1983, 119] terminology) may be seen as an embodiment of the generalized other which is incorporated into the self as it develops over time. As Ferguson notes:

> All selves define themselves, at least initially, by reference to the standards of particular others and of the generalized other. The very act of thinking requires the generalized other because it consists of an internalized use of symbols that are socially defined (Ferguson 1980, 155).

The standard against which women judge themselves--the "rules" they perceive to which particular others and the generalized other cohere--are likely to have been established by men, who "more likely occupy positions of power, authority and prestige in society" (Ferguson 1980, 156). The situation of the public mental health consumer, whether man or woman, within the "professionalist system of care" (Freidson 1970) elicits a "reference to the standards of particular others" comprised by mental health professionals. When the mental health consumer experience is prolonged (which is true for the people in the research sample consulted for this project), the generalized other, whatever its initial form, may merge over time with the "standard of reference" offered by the particular others (professional practitioners) with whom the consumer continues interactions. Ferguson's comments about women, below, may also apply to those who share a subordinate social position:

> ... women are unable to define the situation within which they must act, or at least they cannot define it as extensively and as effectively as men can. Because women lack the necessary control over the relevant social objects, including the norms and rules of the generalized other that govern the conduct of the sexes, they are not in a position to define their own situation, and so they are forced to accept the definition of it that is imposed by men (Ferguson 1980, 157).

Ferguson argues that women lack "necessary control over relevant social objects," judged by their general inability to consistently define their own situation. Mental health consumers in relation to professional providers also manifest a general inability to consistently define their own situation. Although disproportionate numbers of women are identified as mental health consumers, as a group they are subject to imposition of others' definitions for their own situations. This affects both genders.

The opportunity for others' to impose definitions is a structural property of the social system, whose rules and role prescriptions accord professionals this authority. Additionally, the personal experiences of persons labeled "mentally ill," i.e., emotional problems and other coping difficulties, intensify the effect of this imposition by reducing individual abilities to counter definitions of self or situation offered to them by others. The definition of the situation applicable to them is implemented (or imposed, in the case of court commitment) by professionals to whom they have turned for "treatment." The dynamic that impels inequitable power relations between men and women parallels the inequitable power relation between mental health professionals and consumers of their services:

> Power, whatever its specific form, is the ability to define the situation within which another person acts by controlling the relevant social objects. ... Power can be exercised most blatantly against those who have no defense because they have been convinced they deserve the subordination, because their problems are defined as within themselves. ... The subordinate must take the perspective of the powerful in order to anticipate commands and avoid punishments. The powerful need not do so, because they are able to enforce their definition of the situation without such tactics (Ferguson 1980, 159,160, 165).

In the generation of social practices which correspond to and reproduce social "rules" about women, women in this society remain vulnerable to definitions of others which they cannot reject (having learned the internalized symbols of the generalized other involved in cognitive processes). It is also difficult to supplant these definitions. In part, because the early definitions of self and position are internalized and beyond reflection; but also because structural properties of the social system ("rules"/role prescriptions) preclude their participation in defining their own situation.

Similarly, the generation of social practices called mental health care treatments correspond to and reproduce social "rules" about "mental patients," which can be identified as institutionalized mentalism. Rendered vulnerable by (personal and/or social) coping difficulties, mental health consumers cannot reject their definition as "mental patient," nor can they supplant it because the "rules" (institutionalized mentalism) prohibit their participation in defining their own situation.

Broad conceptual theories such as Ferguson's do not reflect the situation of each woman in society, and of course there are individual exceptions to the general processes she identifies. By asserting that these processes parallel experiences of people labeled "mentally ill," I do not intend to suggest that these processes affect each individual consumer. They are identified here as processes which generally affect the nature of mental health consumerism. They are the same processes which the Alternatives By Consumers organization confronts in their individual and group advocacy efforts.

Consumers' understanding of their "private troubles" is informed by knowledge developed in a society-specific, sociocultural context. Disturbances in self experience (manifested by coping difficulties) are emotional or "mental" problems. They (or others acting on their behalf) know who to turn to for advice (i.e., the socially sanctioned mental health care practitioner). Thus, "the dialectic of domination is complete when the suppressed acquiesce in their subordination" (Ferguson 1980, 143), and consumers learn to define themselves as "mental patients."

The individual psychotherapy situation is the most common first route to subsequent mental health care in the system. It is defined within the social stock of knowledge as a vehicle for restoration or development of autonomy, which can here be considered as the ability to define individual situations. And yet:

> Self-disclosure is a means to enhancing another's power. When one has greater access to information about another person, one has a resource the other person does not have. Thus not only does power give status, but status gives power. And those possessing neither must contribute to the power and status of others continuously (Henley and Freeman 1975, 394-95).

The irony of seeking professional help to reclaim individual autonomy when the situation is characterized by inequitable power relations has been criticized from various vantage points. Professional mental health care has been cited as responsible for causing emotional harm to individuals (e.g., Masson 1988), and emphasizing institutional conformity (Bellah et al. 1985, 124ff) (among others). When women, mental health consumers or other oppressed segments of the society believe they are the cause of the woes they confront, their definition of the situation as presented to <u>and</u> accepted by them cannot change. As Ferguson notes:

> ... no oppressed group ... can forge its own identity solely by an internal quest because its oppression is defined and maintained by an elaborate network of institutional linkages that exist outside the individual and have a facticity that cannot be denied (Ferguson 1980, 130).

These comments again echo the situation faced by consumers as much as they inform our social understanding of women. For consumers, the network of institutional linkages maintaining their oppressed position include the family, school, work settings and the mental health care bureaucracy itself. This underscores the need to include institutional analyses as a crucial aspect of comprehending the mental health consumer experience: inability to define their own situations is compounded by a network of institutional barriers.

Eliminating the practice of individual psychotherapy (as one piece of the institutional network precluding self- or group-generated definitions of self or situation) is too simplistic in its approach to this multi-faceted dilemma. It denies the everyday reality of many mental health consumers who live excruciatingly painful existences. Their accommodations to their experience of unrelieved vulnerability (i.e., powerlessness and lack of autonomy) often result in isolation and withdrawal from social situations where potentially positive interactions might offer "emotional correction" to past traumatic interactions. And yet, mandating their participation in mental health treatments (regardless of the attribute used to deem this necessary) deprives them of autonomous choice to seek treatment, denies their civil rights, and increases the likelihood that, as a reluctant or recalcitrant patient, they will be subject to the most invasive treatments (e.g., drugs, hospitalization, electroconvulsive therapy) that require the least understanding of their situation (as Karon [1986] pointed out). Even if psychotherapy (the least invasive of the treatments available) was the only mandated treatment, the forced nature of the interaction for both parties might attenuate the "emotional correction" it could otherwise offer.

Drawing on the literature of Ferguson, Mead and Giddens discussed in this fifth category, it can be argued that changing mental health care practices can initiate a change in the "rules"--and role prescriptions--for mental health consumers. Since achieving liberation necessarily involves "freedom and compassion, ... [and] defining one's own situation and taking the perspective of the other" (Ferguson 1980, 159), it is clear that changes in treatment practices must embody these elements. The positive outcomes of such efforts are instructive, supporting the claim that changing practices can change treatment outcomes. Such change is currently underway in the Boston area.

Not surprisingly, it was largely (but not solely) impelled by feminist researchers-practitioners (Jean Miller, Janet Surrey, Judith Jordan, Irene Stiver) frustrated in attempts to assist their clients in attainment of mental health ideals defined from a male vantage point.

> We're not just involved in reexplaining or reunderstanding the psychology of women. We feel that we may be involved in a paradigm shift from psychology of self to the psychology of relationship and connection ... these are human relationships, not just male or female" (in Robb 1988, 56).

The "theory of empathy" developed by this cohort of women (named above) has been formalized in the women's studies program of the McLean Hospital in Boston, "the very heart of the psychiatric establishment" (Robb 1988, 52). This inclusion is important because it acknowledges the contribution of a changed perspective on human relationships, but also because it suggests that the (disproportionately white, male) practitioners in the "psychiatric establishment" recognize the need for better understanding--and change--in the theories that undergird psychiatric practices and conceptualizations of "mental illness" and "mental patients" (disproportionately women and/or other minority population members).

In the description of the theory following, the strains of "freedom and compassion, ... [and] defining one's own situation and taking the perspective of the other" (Ferguson 1980, 159) are clearly heard:

> Mutual maintenance of close relationships, the ability to listen evocatively so that other people feel empowered to share their feelings as well as their thoughts, and the ability to feel for other people and to express feelings fluently are held up as ideals. ... [It is] a model of growth through addition and enlarging relations and relational context ... quite different from a [developmental theory that stresses] the process of separation and individuation and the achievement of independence and autonomy as the hallmarks of maturity (Robb 1988, 47).

Importantly, development and embrace of this theory has changed the practice of psychotherapy for these practitioners and the people who consult them: "I share much more of myself [in the psychotherapy sessions I conduct]. I am much more engaged with the other person" (Striver in Robb 1988, 47). Self-disclosure by the therapist attenuates some of the power differential in a consumer-provider interaction and is experienced as freeing to the practitioner; taking the perspective of the other (i.e., being "more engaged" with the person seeking consultation) communicates compassion. As the therapist is liberated through freedom and compassion, the relational context of the interaction changes. As guide and behavioral example, the therapist communicates the value of defining one's own situation and taking the perspective of the other to the consumer of psychotherapy. In this example, the therapist can enhance consumers' efforts to understand their own (and their peers') situation in a social context.

As the practice of therapy changes, the "rules" of mental patienthood change as well. When the relational context is included as one of many possible foci in psychotherapy, consumers' experiences in the network of institutional linkages that maintain negative definitions of self can be included in the discourse. As these reflections are included in the dialogue between provider and consumer, they circumvent the need (or theoretical mandate) to posit the consumers' problems as solely "private troubles." Through the psychotherapeutic relation and its attendant processes of self- and social reflection (i.e., compassion for perspective of another), the consumer can reclaim autonomy and power (i.e., ability to define one's own situation). Thus, changes in the practice of psychotherapy, a cornerstone of contemporary mental health care treatment, can lead to empowerment of individual consumers.

When individual consumers learn that interdependency, or relation, is important to their own growth, they can communicate this knowledge to their peers in the care system. Enabled by a deeper understanding of their contextual experiences, individual consumers may well become empowered to share this knowledge with their peers and/or organize other consumers to marshal a challenge to social relations and practices which alienate in favor of those that enable social connections between people. Through these changes, the practice of psychotherapy no longer *necessarily* cultivates "institutional conformity" (Bellah et al. 1985) nor breeds "emotional tyranny" (Masson 1988). When consumer-run organizations such as Alternatives By Consumers provide opportunity for extended interactions among peers, developing a community which values uniqueness of individuals _and_ meaningful relationships among its members becomes possible.

The extent to which this possibility has been realized --or thwarted-- by the actual practices of the mental health care system of which Alternatives By Consumers is a part, will be explored in following chapters. The discussion allowed by reviewing works in this fifth category of literature provides one means to assess the extent of this realization.

Conclusions

My organizing rubric in constructing the synthesis of perspectives represented in this literature review presents a bidirectional and dynamic relationship between structure, process and outcome factors. That is, the political economy, as structure (comprised of reproduced social practices), molds and influences the processes of the social relations of production. Social actors reflect these influences in the types of conceptual (e.g., definitions of "mental illness") and material productions (e.g., psychotropic medicines and other invasive mental health care treatments) they create, seen in society as outcomes of the scientific processes involved with mental health research. But the "flow" from structure through process to outcome is not one way. Outcomes also affect the social processes among actors which will help alter or maintain the structure of the political economy through continuation of social practices defined as mental health care, and through continuation of social practices defined as capitalist, patriarchal, racist, etc..

The conceptual outcomes of interest here are created at three levels: society-wide, within groups, and within individuals. The "isms," the ideologies, and the typifications of consumers are socially produced and pervade society. Capitalism and patriarchy, as institutionalized social tenets, imbue society with definitions of "appropriate" mental health care for consumers deemed "mental patients." The patriarchal and professionalist care system decrees the "appropriate" kind of care for people so defined (i.e., invasive treatments requiring no understanding of the person treated), and the best provider of that care (i.e., predominantly white males).

At an intermediate level, conceptual productions are produced as policies and/or programs of mental health care by different social aggregates. Mental health care professionals (i.e., practitioners, administrators, planners and teacher-researchers) comprise one grouping of interest; alternative policies and/or programs, such as that developed and implemented by the consumer-run organization Alternatives By Consumers (ABC), is another. Professionals and consumers alike are guided by definitions of "mental illness," although professionals more likely apply the formal definitions (taught by teacher-researchers in institutions of higher learning) in the social practice of mental health care treatments. Less bound to these mainstream practices, the innovative programs developed by consumers reveal inadequacies in their received definitions of self (as "mental patient") and situation (dependent on professionals for restorative mental health care). The solutions consumers propose as correctives for these inadequacies change consumers' understanding of the information they receive from professionals. Moreover, if the new information is attended to by professionals, especially practitioners, then subsequent conceptualizations of consumers and the difficulties confronting them can begin to change.

Finally, these conceptual productions can be seen in individual outcomes or consequences, revealed in the social histories of consumers. At the individual level, the degree to which consumers, and significant others in their life (family, friends, former co-workers, etc.), accept or reject definitions of self and situation as provided by practitioners can be seen. This information can be assessed in juxtaposition to different information received, accepted or rejected, through participation in the consumer-run organization (ABC). (It is also on the level of the individual that the impact of material productions in the mental health care sector, i.e., usual and customary treatments, can be explored in their effect on the subsequent careers of mental health consumers.)

Looking at this literature from the mental health consumer vantage point allows a certain perspective on social change to emerge: consumers can provide new knowledge which will affect both outcomes (e.g., definitions of "mental illness" and mental health care "treatments") and structures in the political economy of mental health care through provision of experientially based assessments of standard mental health care. Changes in the quality of social relations (e.g., in the practice of psychotherapy), directed by new information, will affect both outcomes and structures through the interdependence of these two factors.

Informed by consumers' needs, it seems that the strategies most essential for changing social relations in the mental health care system are: preparing for inevitable conflict between consumers seeking to define their own situations and professionals who routinely implement definitions of consumers as "mental patients" (whose characteristics are known and codified); achieving empowerment/ability to define one's own situation for consumers of the mental health system; knowing the allies in consumer-impelled change efforts (among professionals, researchers <u>and</u> consumers); and identifying <u>all</u> the players in the struggle (i.e., defenders of the mental health care system at federal, state and local levels and within institutions of care and education). It is for these reasons that literature in the fourth category, which connects micro-level and macro-level realities facing mental health consumers, is so important to this project. I intend, through this project, to contribute to this small, but growing body of works.

In the next chapter, "Methods and Methodology," I review additional literature contributing to the research design and the rationale I developed for its implementation.

CHAPTER END NOTES

(a) In the following passage, professional consumer advocates (Rose and Black 1985) comment on the effects of poorly designed rehabilitation programs:

> ... Participating in such programs ... reaffirms the participants' infirmities by reproducing their diagnoses and the social system which assigns them ... overtly developing the 'as if' world of mental health agencies: the 'as if' aspect reflects the fact that programs often operate as if the substantive content of their program were real, 'as if' it were possible for [a consumer with years of inpatient experience] and the physical demeanor and income that comes with it could, after attending a pre-vocational program, progress through an occupational therapy program to a vocational rehabilitation program to an on-the-job training program, then enter the competitive labor market and live happily ever after ... These programs are typically infantilizing, disconnected from the concrete reality of either life on the ward or in the community and are therefore humiliating (Rose and Black 1985, 103).

(b) An expatient reflects on the conditions that elicited her return for inpatient care, which Talbott (1984) and other mental health professionals would likely label a "relapse:"

> I was in the hospital for 3 weeks. My belief that I was in a caring, therapeutic atmosphere never wavered ... When I was discharged, I expected to feel better. I went home--and discovered that I still couldn't get out of bed or stop crying ... when I was home, it had seemed that I could get away from the terror I felt by coming back to the hospital ... Rather than wanting to be well (which I began to think was impossible), I wanted only the security of [the hospital], where I still thought I would find the cure for my unhappiness ... In the patients' jargon ... life in a mental hospital was defined as being *inside*, safe and protected ... Was this what the rest of my life was going to be? ... I didn't want that, but I had no idea how to change ... (Chamberlin

1978, 25, 26, 29, 30, 34).

Chamberlin was diagnosed as a schizophrenic during her inpatient career. The dynamic in her response to hospitalization, its ineffectiveness for her, and the paradoxical reliance that she develops on the hospital despite her negative experiences there well illustrates how "relapses" occur once people are defined as "mental patients." As consumers of mental health services, they come to embrace the definition of self--and hospitalization need-- offered by professionals in mental health care. As seen in the quoted passage, once these definitions were embraced, she no longer "knew how to change" without tutelage from mental health providers. It is equally important to perceive the effect of her hospitalization experience on her subsequent return to the hospital. Her "relapse" seems less inspired by symptoms (as Talbott would have it) than by what she believed the institution could offer her (i.e., a cure for unhappiness).

(c) For a brief but cogent discussion of Clifford Beers' contributions see Armand Mauss (1975, 331-333). For an historical account of his contributions, see Grob (1983, 146-158). For a comprehensive view of Beers' experiences and recovery, consult his autobiography, <u>A Mind that Found Itself</u> (Garden City, NY : Doubleday, 1953).

(d) "Biological determinist thinking is an important part of the philosophy underlying the political program of the New Right in the U.S. today, expressed in its efforts to reinforce the patriarchal family and reinstate it as women's exclusive sphere by withdrawing programs for social welfare, removing women from the labor force, and bringing their sexuality and reproductivity more fully under state and male control ... Woman is to be legally defined and socially confined as mother, reproducer, and nurturer; dependent and subordinate" (Eisenstein [1982] and Bleier in Bleier 1984, 11).

(e) Bleier's (1984, 9) phrase, "reactionary political applications" as a descriptor of the Nazi reliance on biological determinism to direct social change is a gross understatement of the reality that "mental patients" faced in Hitler's Germany.

"During the years 1939-1945 the number of patients in the psychiatric hospitals of Berlin fell to a quarter of the original total ... [in other parts of Germany and Austria] the number of patients was reduced from about 300,000 to 40,000 ... A new treatment was indeed responsible. The new "treatment" was mass murder" (Hill 1983, 8). "For example, in 1941 the psychiatric institution Hadamer celebrated the cremation of the ten thousandth mental patient in a special ceremony. Psychiatrists, nurses, attendants and secretaries all participated. Everybody received a bottle of beer for the occasion" (Wertham 1966, 157 in Hill 1983, 9). By conservative estimates, 275,000 psychiatric patients were killed during this period. "The psychiatric term for the murders was "euthanasia" and the diagnosis for which such treatment was recommended was "life devoid of value" (Hill 1983, 9).

For a comprehensive discussion of this tragedy, see Hill (1983, 8-15) and/or Wertham, F. (1966). In a related vein, for discussion of the link between Carl Jung and his participation with the Nazi regime, see Masson (1988, 94-123).

(f)For an indepth discussion of moral treatment, its history and contemporary applications, see Bockoven, J.S. (1972). _Moral treatment in community mental health_. New York: Springer.

CHAPTER 3

METHODS AND METHODOLOGY

Introduction

Assessing trends in consumer-related literature that perpetuate notions about recipients of mental health care as well as standards of treatment deemed most effective for them, I developed a plan for this project that would allow an accurate portrayal of the mental health consumer situation as perceived by the individuals involved. This chapter details the research philosophy used to develop a specific research design, how that design was implemented, how data were analyzed and the interview sample characteristics.

While doing field work at Alternatives By Consumers in 1983, it appeared that quantitative measurements would inaccurately portray the work of this small organization. The quality of interactions seemed a determining feature in whether consumers seeking assistance from staff and volunteers at ABC resolved the immediate crisis that brought them there.

Quantitative analysis informs the research base from which most treatment decisions in the mental health system emanate. Research based on quantitative methods also supports most policy decisions. This research base helps to maintain the status quo in mental health care practices. It justifies cost-effectiveness of certain treatments (e.g., mass administration of psychiatric medications is less expensive than more staff or improved rehabilitation programs) but it will not point to errors in treatment or practice because the qualitative outcome--the actual treatment reality experienced by the person--is not considered.

In consideration of these trends, I focus this study on the qualitative effects of the care system and the Alternatives By Consumers (ABC) organization on real people, who cry, who hurt, who do not get better, and who do get better despite great odds. Their story, and the problems of the mental health system, cannot be revealed by statistical analyses alone. Thus, I approached this research with a key methodological question in mind: How could a critical theory of mental health consumerism be developed using qualitative methods?

Research Philosophy

The research design for this project demanded recognition of the needs of this special population (e.g., careful and patient listening) and their efforts to address problems in mental health treatment practices and policies (e.g., their peer-to-peer, and consumer-to-system advocacy/service work). It is not possible to approach these issues with a pretense to a "value-free sociology." Rather, the methods used have been a means toward a specified end: change which "mobilizes the innovatory capacity of ordinary people" (Silverman 1985, xi). Drawing on the work of critical social science theorists, I also wanted to design this project to serve an end goal of "emancipatory knowledge."

This reference to emancipatory knowledge derives from the work of Jurgen Habermas, a member of the Frankfurt School of critical theory. In his work <u>Knowledge and Human Interests</u> (1968), Habermas suggests that the social framework which defines types of knowledge to be sought also provides the basis on which the knowledge is to be evaluated. Discerned "truth" is that which fits realities objectified by the sciences themselves. The instrumental bias of the sciences can only be overcome by "...incorporating in their consciousness an interest which directs knowledge; an interest in emancipation going beyond the technical and practical interest of knowledge" (Habermas 1968, 9). Thus, the interest that directs the knowledge sought in this research is emancipation. Transformative action, then, depends on what I refer to here as "emancipatory knowledge."

Brian Fay (1987) suggests that transformative action is achieved by means of "rational scrutiny."

> According to critical social science, the suffering of a group of people occurs in part because they have had inculcated into them an erroneous self-understanding, one embodied in and supporting a form of life which thwarts them. The aim of critical science is to stimulate these people to subject their lives and their social arrangements to rational scrutiny so that they can re-order their collective existence on the basis of the scientific understanding it provides. Critical science wishes its audience to reflect on the nature of its life, and to change those practices and policies which cannot be justified on the basis of this reflection (Fay 1987, 66).

The "ordinary people" of the "audience" are mental health consumers, professional providers, mental health workers, professional and lay-advocates, families, and friends of people receiving treatment for coping difficulties in the mental health system. They constitute an audience which can be mobilized to "rationally scrutinize" the basis of the collective existence now shared. The collective existence of consumers, and the treatment provided to them within the mental health system, reflects the "scientific understanding" of the nature of people and the nature of the problems they must overcome. This understanding is broached by professionals in the field with enough power to implement such definitions.

Many consumers believe the treatment system must be transformed; individual experiences shared in communities of consumer peers has stirred desire and consciousness of alternatives to traditional treatments. This may or may not lead to further reflection on "re-ordering lives and social arrangements" to alter collective experience, but it is this latter vision to which this research is dedicated. Transformative action may be spearheaded by mental health consumers, but it is action that will enlighten the larger audience.

My direction in this research was guided by attention to the question: How do researchers in the sociology of mental health/medicine know what they know--or need to ask? The tenets of phenomenological sociology offered heuristic direction. Moreover, they complemented and informed the practice of grounded theory research (Glaser and Strauss 1967), whose procedures I followed closely. (Specifics of grounded theory procedures appear later in this chapter.)

The vantage point of "phenomenological sociology...involves understanding as its core process and social actors as its principal focus" (Rogers 1983, 139). The interplay between actors' meaning-making, actions and talk, and social structure becomes invisible and inaudible when actors are not consulted as part of a research study. Because "(e)very effort to understand anticipates meaning" (Gadamer in Rogers 1983, 144), the methods of inquiry--whom we chose to talk to or observe, the questions we chose to ask or ignore, the settings in which we do our research--affects what can be learned and subsequently applied. Without consulting the actors involved with the phenomenon labeled "mental illness," any outcome researchers empirically enumerate displaces the link to the phenomenon most integral in the study--the <u>meanings</u> of events for actors in the realm called mental health care. Not going to the source of the phenomenon, to which all structures (e.g., mental institutions, the medical sector, psychiatry), processes (diagnosing, treatments, career trajectories) and outcomes (incurable "illnesses," "good," or "poor" prognoses, recovery or permanent disability) are referenced leaves the original "subjects" abstracted and objectified, and prey to others' interpretive schemes.

I did not want to subject people in this research project to my own interpretive schemes, i.e., that primary and secondary group affiliations had great affect on subsequent coping difficulties; and that the effects of the political economy on individual situations could not be ignored. Nor did I want to wholly rely on consumers' verbal understandings that parroted the "scientific understanding" of "mental illness" as a medical ailment (which I suspected most had internalized during their years of treatment). I was struck by the recognition of this dilemma, and suggestions for its resolution, afforded by what Rogers (1983) describes as phenomenological sociology. Use of this material also enlightened my application of grounded theory research procedures.

In sociological research informed by phenomenology tenets, reflexivity is a cornerstone. "The true method follows the nature of things to be investigated and not our prejudices and preconceptions" (Rogers and Husserl in Rogers 1983, 67). This occurs by shifting the focus of study from the commonsense experience of objects (of consciousness) to the phenomenological experience of phenomena.

To achieve release from preconceptions and apprehend the meanings intended in consciousness, Rogers asserts that a tripartite procedure is required, constituted by an epochè, an eidetic reduction, and the phenomenological reduction. The epochè involves "bracketing the natural attitude,"

> our everyday acceptance of the world as being something "out there" for us to experience. It is the pervasive unquestioned assumption that our everyday surroundings are real and provide the same reality for others. .... [The] natural attitude is not a particular or explicit act of consciousness; it is something which pervades, and is implicit in, all mental processes which are directed toward the world (Jennings and McKenna in Jennings 1986, 1237).

Rogers explains the significance of the epochè this way:

> When the epochè is in operation, whatever is known is known as essential and necessary. [It] thus opens up a rich sphere of experience different than common-sense experience (Rogers 1983, 71).

The epochè does not lead to a denial of the natural (or taken-as-granted) world, it simply refers to suspending the everyday "believing-in-the-world...for the methodological purpose of 'purifying consciousness'" (Jennings 1986, 1237).

The second phenomenological method is eidetic reduction, which holds an object of consciousness (while bracketing the natural attitude) as an exemplar of "pure possibility," i.e., that the object of consciousness is being seen in its "essence" or pure form. The eidetic reduction employs "free variation" (i.e., runs through a number of possible object variations) to determine if the object of consciousness is an example of pure essence or whether it can be seen as a 'variation on a theme,' the theme being pure essence. "When that object is not imaginable as a variant of the variant being imagined, the investigator has reached an eidetic limit" (Rogers 1983, 72).

The natural attitude requires that the investigator suspend the everyday belief in the facts of the world, and the eidetic reduction requires that the object of consciousness investigated be explored as an example, rather than taken as a fact itself. By running through all the possibilities of what the phenomena of study might or might not exemplify, its essence is sought--the core element(s)--that makes this particular object an exemplar of a certain "class of possibles."

> The essence...is what remains invariant throughout the imaginative variation of the original object. The essence

> is those elements without which an object of this kind cannot be imagined. It is those conditions every variant must meet as an example or manifestation of a specific class of possibilities (Rogers 1983, 72).

Phenomenological methods support the inductive analyses of these research data. The methods are analogous to the "grounded theory" technique of field research (see Glaser and Strauss 1967) that I followed. The epochè and the eidetic reduction methods are similar to the process of searching through field notes for a core variable that will explain what the data are about, or what they are a study of, toward the end goal of a theoretical break-through (i.e., the discovery of a theory grounded in the data). "Bracketing the natural attitude" (the epochè) is analogous to suspending ordinary sociological assumptions while seeking to code the activities, conversations, and observations into categories of meaning that members of the situation intend. For example, if someone at the Alternatives By Consumers' center tells another person "I think you need your meds [psychiatric medications]!," the intent of the communication may be humor (at the antics of the other person) or an affectionate rebuke (for short-lived, but untoward behavior of the other person), rather than a genuine belief that the person needs sedation.

The eidetic reduction accurately describes the process of discovering a "core variable." After establishing overarching codes into which most of the research data "fit," categories are searched repeatedly for social or psychological processes that best capture what is happening in the data. In this winnowing of possibilities (by running through imagined variants of the variants to discover whether the object of consciousness is an example of a class or an exemplar itself), the core variable emerges, evoking the essence of actors' intentions in speech and action.

For instance, I once thought that the "core variable" in my 1983 field research at ABC was a concept I called "role-bridging." I believed that variations in the ABC's executive director behaviors toward consumers versus mental health professionals were best explained by his attempts to, on one hand, be a role model for peers and on the other, bridge the consumer-realities with system exigencies. (This is discussed in detail below.) Employing eidetic reduction during this project, I came to see that role-bridging was not an exemplar/core variable. Rather, it is one example of the exemplar "defining the situation," the core variable that emerged during this project. A good indication of its genuine fit/exemplar status is that it subsumes the 1983 data and the more elaborate data collected for this study.

There is also a parallel to the generation of grounded theory and the "phenomenological reduction" procedure. This reduction transforms the essential acts of consciousness themselves into the subject of analysis.

> Hence, in the reduction, there is only a shift of focus from studying the specific objects of a conscious experience to studying the essential character of the acts of consciousness, which "intend" or "give meaning to" various events or objects...(T)he purpose of the reduction is to transform the field of study from "psychological consciousness," which is purely concerned with the empirical facts of experience into "pure consciousness," which is the field where essences can be grasped (Jennings 1986, 1237).

The strategy of grounded theory similarly seeks to transform the study of meaning-making talk and activities (i.e., social constructions of reality) into its most essential form. Here, this means discovering a theory that articulates the "core truth" shared by participants in the ABC consumer community (e.g., `we can define the situation' [or change, amend, and propose it] and reject professionals' definition of ourselves [or of the label mental patient]).

This analogy between inductive analyses and the methodology of phenomenological sociology illuminates the import that phenomenology holds for studying the phenomenon known as "mental illness." It cannot be approached without suspending common-place sociological assumptions, nor can it be described or explained by medical determinism. Many possibilities must be examined, and many "variant examples" will enter into understanding the meaning of events in mental health care practice and personal experiences. The phenomenon--the conscious meanings constructed by consumers--must be the crucial focal point for research in this area. This reasoning supports the research design, its implementation, and strategies for analysis.

Research Design

In retrospect, it seems more appropriate to call this research design a "research evolution." When I was first exposed to the consumer organization Alternatives By Consumers (ABC), I was a graduate student fulfilling requirements for a field methods course taught by Dr. Barrie Thorne at Michigan

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State University in the fall of 1983. For nine weeks, three hours each Thursday, I went to the ABC office, observed activities and interactions and wrote field notes on my observations. During the final week of in-office observations, I also interviewed two people, the founder of the group, Steven Ashton, and a participant and ABC Board member whom the founder portrayed to me as an "ABC success story."

I had met Ashton in 1980, before I took up graduate studies, when we were both working in human service occupations in the community. I knew he was respected by mental health professionals and consumers alike, and knew his "straight from the heart" manner of public speaking was powerful. He was in the initial organizing stage when we met, and I had heard much about the formation and evolution of ABC from him. Three years later, two research questions seemed appropriate for the 1983 field course study: What made ABC work? Was the organization's success solely attributable to Ashton's charisma?

After collecting field and interview data on these questions, I coded the notes and transcriptions into categories appropriate for analysis. Inductive analyses were used for the field methods course term paper and centered on the apparent core variable in the data, "role-bridging." This concept seemed to embrace a central activity of Ashton in his leadership role: providing a bridge between the world of the "mental patient" and the world of the professional mental health care provider. In this work, Ashton's "role-bridging" encompassed a variety of properties. Assumption of certain demeanors, use of professional and "lay" language in creative ways, use of humor to cajole reluctant individuals into different visions of themselves, and affirmation and support of services that were viable in the mental health system seemed to capture the most important of these.

During this study, I discovered important aspects about the work of the organization and insight into Ashton's efficacy as a consumer advocate. I developed friendships with some of the volunteers and increased my understanding of the living conditions--and obstacles--faced by consumers who relied primarily on the public mental health system for emotional care and on the public assistance system for means of subsistence. Although I did not realize it at the time, this early foray into establishing rapport with consumer volunteers became the stepping stone of acceptance that allowed my later return as a volunteer, and still later employment as Associate Director for one of ABC's special projects.

I kept in touch with Ashton after this early study as I returned to school to finish course work and solidify ideas for the dissertation proposal and research. He knew of my research interest in ABC and was pleased when I returned in the summer of 1986 as a volunteer for the organization, and to collect additional field data.

There had been dramatic changes in the organization since their receipt of on-going funding from the local Community Mental Health Board in 1983. As their funding expanded, so did the scope of their services and outreach to other parts of the state. Noting these changes in the organization, it became apparent that a case study of ABC would need to be a part of the developing research design since the field data did not seem to be tapping the intra-organizational change I perceived.

At the end of the summer, a paid position at ABC unexpectedly became available and Ashton offered it to me. As noted above, my history with the organization (through field research and volunteer help) was a key factor in Ashton's offer of employment. Despite my difference in status (i.e., I was not a public mental health consumer), I was apparently trusted by Ashton and other staff persons at ABC. I accepted the position, realizing that my skills could benefit the organization and that taking the position would increase my working knowledge of ABC activities. As Associate Director for one of the special projects offering consulting skills to other consumer groups throughout the state interested in forming "ABC-like" organizations, I compiled information for quarterly progress reports and assisted Ashton with his "hands-on" organizing work in other Michigan communities. I did learn a great deal in the job and felt privileged to be a part of ABC's work. I established new relationships with consumers of ABC and those in other cities and enriched my understanding of consumer issues. The reports assembled during my employment at ABC added to other documentary data located while I worked there. These documents were rich sources for nonstatistical content analyses. These types of analyses capture organizational effects not otherwise accessible, so they were also incorporated into the final research design.

I also knew that employment would allow me to become better known to people of the organization prior to recruiting volunteers for the in-depth interviews I wanted to do with ABC participants. I knew building trust between myself and potential interview volunteers was paramount. Sharing substantial periods of time is one feature in its initiation. Another critical aspect is openness and honesty about intentions. It was necessary, then, to establish that I had accepted the job for dual purposes: to help Ashton and ABC in the special project work, but also to proceed with research on the group. As I had done during 1983 field work, I took many opportunities to volunteer information to people about my "dual status," i.e., I worked for ABC in this role but I was also doing research at ABC for my degree from Michigan State University. At no time did I ever intentionally deny or "cover-up" my researcher role.

In practice, I was most often consumed by the demands of the job at ABC (paperwork, travel to different parts of the state, correspondence, impromptu discussions about mental health issues, and requests for advice about immediate problem-solving). My interactions were with people who, by and large, shared histories characterized by repeated instances of psychological abuse from many people who knew them, including their family and friends. As a survival strategy, it seemed that they had developed "allergies" to interpersonal lies and dece

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deceit.[1] I understood that they little reason to trust me simply because I was there. Consumers usually turned to ABC during times of crisis and their emotional neediness constrained me from the "luxury" of assuming certain behaviors with them. Their needs demanded immediate attention, compassion and shared person-to-person intimacies that I could not escape, short of walking off the job.

The predominant ethos at ABC is honest disclosure. In this situation, had I <u>wanted</u> to deny who I was or what else I was doing in addition to working in my position there, it would have been nearly impossible to do so. In the months before interviewing started, my authenticity was repeatedly tested. Had it been found wanting, I do not believe people would have volunteered for the interviews. The "consumer grapevine" was a real source of information for people at ABC. Few events at the organization escaped commentary or inclusion on its "wires," and as "new kid on the block," I was sure to be a topic of conversation. Although I knew most of the people in the interview cohort through interactions at ABC, my suspicions about the consumer grapevine proved accurate when I interviewed with[2] people <u>I</u> didn't know well but who did seem

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[1] This meaningful conceptualization is used by Hannah Green in <u>I Never Promised You a Rose Garden</u>, New York: Holt, Rinehart & Winston, 1964.

[2] I am intentionally using the phrase "interviewed with people" rather than a more straightforward construction, such as 'I interviewed people...'. My intention is to draw attention to the shared nature of the interview experience, and distance myself from language that implies I did something <u>to</u> people volunteering for the study. In fact, the interviews were joint events, providing a literal forum for "inter-views."

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to know much about me. In hindsight, it appears that my exposure to this population through employment at the organization clearly facilitated successful entree to the interview volunteers.

In these ways, then, my research design evolved to assume its final form. It incorporates these methods of data collection: scheduled observations at the 1983 office site with compilation of detailed field notes; personal interviews with Ashton and the ABC Board member in this same time-frame, which were tape recorded and transcribed verbatim; attendance at formal presentations made by Ashton for ABC during autumn, 1983 on which field notes were written; compilation of written documentation from 1983-1988 on Ashton and ABC; informal observations at ABC during the summer of 1986 for which field notes were written; "hands-on" work experience at ABC from September, 1986 to June, 1988; and in-depth interviewing with 15 ABC participants, which were tape-recorded and transcribed verbatim. These sources yielded over 300 pages of field notes, more than 1,030 pages of verbatim interview transcriptions, and a veritable mountain of written documents.

Research Design Implementation

The research design is divided into two main parts, a case study of the organization Alternatives By Consumers (ABC), and in-depth interviews with participants of ABC. In practice, various methods of inquiry (participant observation, document analyses and interviewing) combined to inform the res

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research findings presented in Chapters 4 and 5. The discussion following presents an overview of these two main parts.

Case Study

The case study of ABC drew on several data sources: observational, documentary and interview. Without such triangulation, a holistic portrayal of the organization is flawed. An in-depth look at the origins and metamorphosis of the organization within its cultural context, U.S. deinstitutionalization efforts and emergence of mental patients' rights issues, provides an historical backdrop for the experiences of ABC's first "champion" and founder as well as for the analysis of ABC consumers' interviews. The case study is also a necessary prerequisite for locating Alternatives By Consumers within an institutional matrix of the mental health care system in this area and state.

The case study is presented in chronological order to capture the evolutionary nature of change in the organization. The imposition of a stage analysis model (Mauss 1978)[1] on this chronology of events illuminates ways in which ABC's natural history can and cannot be viewed as a "social problem-movement." Because the Mauss model synthesizes dominant theories of social problems and social movements, use of his model allows discussion of strengths and weaknesses in this body of literature and its applicability to this organization.

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[1] See chapter 4 for a detailed explication of Mauss' theory and social problem-movement model.

An ensuing discussion of different theoretical approaches to events in the natural history not captured by the Mauss model enhance the features in the natural history that make this organization unique. In this critique, I also apply my "insider" knowledge about the vision of ABC as a social movement as seen through the eyes of its founder, principal participants, and representatives of social institutions with whom ABC members interact.

Documents used for the case study include written reports submitted by ABC to their funding sponsors; newspaper features on the group and its founder; Community Mental Health (CMH) and Michigan Department of Mental Health (DMH) internal evaluation reports of the group; and journal articles published following the demonstration period for one of ABC's special projects. Documents consulted cover the year of ABC inception (1980) through 1988. Other relevant data are drawn from field notes compiled during 1983 and 1986, and excerpts from interviews.

Interviews

The interview data were collected between September, 1987 and January, 1988. While the interview guide (see Appendix A) structured topical areas, all responses were open-ended. There were five major areas: (1) background information (e.g., family of origin and personal demographics), (2) past history in mental health care (e.g., number and types of hospitalizations, number of therapists consulted, length of time in therapy and/or on psychotropic medications, etc.), (3) present

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situation in mental health care (e.g., number and type of Community Mental Health programs currently being used, expectations about outcome of current therapy, if any, etc.), (4) participation history with Alternatives By Consumers (e.g., year of first contact, extent of involvement, employee or volunteer status, etc.) and (5) solicitation of consumers' ideas for change or improvements in the care system and ABC.

All consumers came willingly to the interview sessions. My surprise was that they came eagerly and stayed long, seemingly hungry for the chance to share their story. I had anticipated problems with people not showing up, either for the first session or for the session(s) that would conclude the interview. This never happened. Only once did someone change their mind about participating, and did so before we had scheduled an interview time. All tolled, 48.75 hours of interview dialogue was recorded which yielded 997 pages of transcription. The average length of a completed interview was 3.25 hours, with a range of one and one-half hours to six hours.

One major shift in the guide was made following the first two interviews, but involved only a change of sequence in the five major topics of the interview. Prior to the change, the likely first break in interview sessions occurred between the second and third sections, but it did not seem prudent to end a session with discussion of past history, frequently associated with pain and trauma. For the third through the fifteenth interviews, then, I modified the sequence so that the topic at the end of the first likely break would be the current situation in mental health care. I felt that consumers leaving an interview session after assessing current particulars would be less likely to experience "emotionally charged aftermath." This change also meant that painful past histories would be dealt with early in the next interview phase, and that the end of that interview would be on topics concerning the consumer's ideas for change in the system of mental health care and the consumer group. Each question on the guide was posed for specific reasons and/or to seek specific information that observational data had not "verified," or had left open to recurring speculation.

There were only two instances of minor factual inconsistencies in the interviews, discovered during verbatim transcription of the taped sessions. Both instances were discrepancies in age at admission to a psychiatric hospital during childhood presented in different parts of the interview. In one case, I could correct the age because the person recalled that she learned John Kennedy had been assassinated while hospitalized. In the other case, the discrepancy was between entering the hospital at age 6 or age 8; I resolved this by adjusting his admission age to 7 years. Because childhood hospitalization data were used only to establish background histories, this latter adjustment has little effect on data analyses central to this project.

A third instance was revealed when a woman called me several months after her interview to tell me that she had altered her rendition of certain events and that she now

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wanted to correct that information. Originally distressed when I encountered these inconsistencies, I came to understand them as part of the context involved with interviewing people from a population that is so routinely discredited by professionals in general and researchers in particular. The two instances of factual inconsistency both occurred with people I had no prior contact with and who fell in the "least involved with ABC" category of my sample (see sample characteristics, following). This suggests that missing sufficient time to build a trust level between us, coupled with their lack of exposure to the dominant ethos of the organization, honest disclosure, combined to allow such discrepancies to occur, whether intentional or not. When the inaccurate information obtained in interview was corrected voluntarily by the woman who called me about it, I saw this as affirmation of the trust established between us. It also appeared that her offering may have been related to an increased involvement with Alternatives By Consumers at the time that she called.

I accept and trust the data supplied by people with whom I interviewed. I believe the overarching dynamic in the interviews was one highlighted by W.I. Thomas, that the veracity of their communications were of less importance than the consequences of their beliefs. They told me the truth they knew. The fact that they shared details of trauma, abuse and long endured pain indicates a trust between us that speaks to the credibility of these data.

While there was an overlay of structure common to all int

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interviews, each situation was unique. People varied in their ability to respond directly to questions posed. For this reason, I altered the cadence of questioning, probing and interjecting to guide consumers back to the topic at hand according to the behaviors I observed with each person. My primary concern was to allow each person unhindered expression. At the same time, it was important to set boundaries on time and topic development as a pragmatic measure to keep my task doable and also as a way of shielding consumers from possible emotional exhaustion or travail that might occur if one topic was dwelt on too long (e.g., their recounting of negative experiences accompanying early hospitalization experiences).

I began each interview by telling the person something about my own past experiences with emotional coping difficulties during adolescence as a way of leveling any perceived status inequality between us, but also as a way of assuring people, especially those who did not know me well, that I was not a mental health professional and that I could empathize with some of their own experiences. This initial disclosure on my part set the tone for the interview: in effect, I was offering an example of disclosures I hoped they could share with me, and providing a concrete example of materials we would discuss.

Recruitment Procedures

At the suggestion of Michigan State University Committee on Research Involving Human Subjects (UCRIHS), the recruitment

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strategy was designed to minimize threats against non-voluntary agreements to interview. One UCRIHS reviewer voiced concerns that because I was an employee of ABC and would be perceived as an authority within the organization that perhaps people would agree to the interview because they feared retaliation if they did not, and/or that they would lose access to the services of ABC if they became embarrassed by their disclosures in the interview and would then avoid contact with the organization to avoid meeting me again. This threat, if realized, would be especially grave in a community where there are no other organizations providing essential services for mental health consumers outside the bounds of the professional care system. The reviewer suggested that a different employee conduct the recruitment sessions, procure a signed informed consent form from them, then let me know how to contact them for the interview date(s).

A second UCRIHS reviewer expressed concerns that some of the specific topics likely to be discussed during the interviews were not expressly stated on the consent form, namely discussion about illegal activities consumers may have undertaken during or after hospitalization, such as use of street drugs and/or manufacture of weapons.

The recruitment procedures followed addressed both concerns raised by UCRIHS and attempted to provide greater anonymity to persons interested in learning more about the interviews but who decided against participating in them. Two hand-lettered signs were posted in the ABC building, one on

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each floor: "If you are interested in being interviewed for a research project, please contact [the current director of one of ABC's special projects] for details." No other announcements were made and it was left entirely up to the people who read the signs to decide if this was of interest to them and to pursue the matter or not. In this way, all eventual participants in the sample were self-selected.

I understand that allowing participants to volunteer for the study presents the threat of bias into project results. That is, people who volunteered to be interviewed may be very different from people who had no interest in volunteering, and similar to each other in ways not possible to discern without random sampling of the population using the organization.

I knew from my history with the organization that a self-selection process would be a likely occurrence with any voluntary activity proposed to people using the organization. As with other volunteer events, people willing to be interviewed would more than likely be able to be interviewed. That is, persons who have severe communication problems (e.g., incomprehensible speech, language disorders such as echolalia, etc.) recognize these difficulties and usually avoid situations where these problems become salient. (Had persons with this difficulty volunteered, I would have to exclude them from the study since analyzing interview data depend on intelligible conversation transcriptions.) I also had to honor the boundaries set on potential subjects for study by Michigan State University: no adult who had been adjudicated legally incapacitated or currently hospitalized (even if out on a ho

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hospital pass) could be recruited for interviews.

In addition to these reasons, I could not mechanically devise a way to achieve a random sample of the population using the ABC organization. In large part, this is due to their lack of written records kept on persons using the organization. Had I attempted to extract a random sample from people who sign-in on daily "attendance sheets" (by which the organization approximates its user totals), I would encounter a similar threat of bias in study results. People who identify themselves by signing attendance sheets may be qualitatively different from people who do not chose to do so. Although names of persons who do not sign in are sometimes added by the director(s) of various ABC programs when they see individuals they recognize in attendance, this process is subject to great variation and/or oversight. Using sheets altered in this way might also violate the privacy of persons not wishing to be identified as an ABC participant, and have serious ramifications for their continued use of the organization. (That is, if they believed their identity were protected by not signing in and I attempted to subsequently recruit them for interviews, there is no reason to believe they would <u>not</u> see this as a violation of trust by the director who had identified them on the sheet. It is likely that in the event, the perception of violated trust would impel them to stop coming to ABC.)

I anticipated that ABC participants, particularly people extensively involved with the workings of the organization (e.

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(e.g., staff and volunteers) might volunteer. My study relied on obtaining interview data from consumers who could provide details about the workings of the organization; its effect on their lives; and its effect on their views about mental health care and related issues. In consideration of my research needs, selected methods, and the contextual constraints on population selection, I abandoned attempts to achieve random sampling. Thus, study results are undoubtedly weighted in favor of people most likely and/or able to become involved with a mental health consumer-run organization. (These issues are also addressed in the "Research sample characteristics" section later in this chapter.)

Before the signs announcing the beginning of research interviews were posted, I approached another staff person at ABC who volunteered her help with recruiting. At the time, she was director of one of ABC's special programs helping consumers in crisis meet essential needs (e.g., procure food, housing, emergency shelter, mental health or medical care, etc.) or process emotional upset that might otherwise result in hospitalization. I purposely selected this employee as the one most likely to reassure consumers in need that no service provision would be denied if they declined to participate in the interviews (my reasons for selecting this particular employee are elaborated below). Although I was also an employee with decision-making authority, I was not directly involved in that program and would be deemed unlikely to affect receipt of services from it.

I trusted the employee who volunteered to help recruit volunteers for the interviews. I had no reason to believe she would present details about the opportunity to interview for a research project in a way that threatened consumers' belief that they would lose organizational services if they did not chose to be interviewed. In my initial approach to her for help, I explained the reason I had been asked not to recruit people directly, stressing the need to allow people free choice about participation in this project. I believe she understood the risks to possible volunteers that I presented to her. She did not report that any interested person verbalized or appeared to be worried about exclusion from ABC services if they did not participate in the interviews.

Additionally, I was constrained in my selection of possible "helpers" in the recruitment process. When I assumed my position at ABC, there were only three other people employed there. The director who offered her help to me had less history with the organization than other employees, being recently recruited for employment herself. I perceived this as an additional advantage, since trust and loyalty to individuals build slowly among this population. (Previous work with the organization and field research there alerted me to this feature.) Thus, I did not believe that people at the organization would acquiesce to interviews simply out of a felt obligation to this particular employee. I also thought it unlikely that a long shared history between this employee and ABC participants would intervene in prospective volunteers' free choice.

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The two remaining choices were both people who had been with the organization for many years: Steven Ashton, the founder, and Karen York, the director of the drop-in center. I believed that their help in the recruitment process would constitute a larger threat to free choice than either I or the woman who had offered her help to me. I perceived that their years of contact with nearly all ABC participants had allowed loyalty and/or trust to become established with many people using the organization. Had they helped with the recruitment process, participants' feelings of personal obligation to them would likely interfere with voluntary choice to participate in interviews.

I also used methods to further reduce the threat to prospective participants posed by selection of the employee offering to help recruit. I believed use of a recruitment tape recording would address concerns of the UCRIHS reviewers, standardize information about the interviews, and limit the amount of explanation that the employee helping me would need to provide to interested persons. I asked that if the employee did not know an answer for a question asked of her, that she contact me rather than provide information that might be inaccurate. She agreed to do this, although the need never arose.

The recruitment tape recording described in detail the probable length of an interview (two-three hours); possible threats to the persons participating (recall of painful memories); the lack of penalty if questions were unanswered or the person decided to stop before completing it; that sessions would be recorded and transcribed; that this information might be used for a research paper I was doing at MSU under supervision; that I may have observed them in 1983 field work and taken notes that might be used in the paper; that each person's anonymity would be protected if information about them was used; and what topics would be discussed during the interviews, including specific mention of possibilities concerning illegal activities (see appendix B for transcript of this recruitment tape). I further arranged that I would have no knowledge of who listened to the tape until I received a signed consent form indicating a desire to participate.

The consent form (see appendix C for full text) reiterated these verbal points but omitted specific reference to illegal weapons and activities. As I explained to UCRIHS in my response to their review, I deliberately excluded reference to "drugs or illegal activities" on the consent form for two reasons. First, I was offering extensive verbal explanations of study issues to people prior to their decision to participate, including note that some of the things talked about may include use of street drugs, use or availability of weapons in the hospital, and/or illegal activities they may have done in the past. These explanations, proffered before the consent form was signed, provided opportunity for fully informed participation.

Secondly, I know that language is very powerful, especially in official contexts. Having verbally communicated possible risks involved in participation, I believed it imprudent to use language on the consent form that might cause alarm. Using explicit terms ("drugs, illegal acts, weapons") on the form may awaken old fears about other consents or waivers they have signed, and later regretted, through years of treatments in hospitals and clinics. Thus, I changed the wording of the point in question to alert consumers to the risks verbally discussed while avoiding language that might frighten people willing to participate. It appears below in its final form.

> I know that some of the things I am asked about in the interview may bring back sad memories and/or deal with feelings or activities that I am sensitive about. I know that I don't have to answer any question I don't want to answer, and I can stop the interview at any time without penalty. I know that anything I say in the interview will be kept in absolute confidence, and I will remain anonymous.

Notwithstanding these preparations, I always made a habit of going over the topics we would be discussing, assuring the person that they could decline to answer questions they wanted to without penalty, and asking again whether it was alright to tape record the interview at the first session. Remarkably, in 50 hours of interviewing, only one person declined to answer one question, and one other person wanted the recorder turned off during a 2 minute response to a different question. My impression is that people with whom I interviewed responded with candor and depth to the questions posed.

Interview Settings

Most interviews were set for evening or week-end hours. To minimize variation and provide a setting likely to be com

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comfortable for the people interviewing, I arranged for all but 3 interviews to be done on-site at the Alternatives By Consumers center. When the interviews began (September 1987), my ABC office was also in the building used by the organization, but no interview was conducted there. Rather, I chose an office that had a door to close for privacy, and also one where we could sit without having either of us behind a desk. This was the arrangement for most of interviews when other people were in the building. On days or evenings when no one else was there, we sat downstairs in the same building, sharing a large table.

On the three occasions when I did not use the ABC building, I used other offices that ABC had leased for one of the special project's headquarters. Although it had the disadvantage of being unfamiliar to the three people whom I met there, it had been visited by two of the three, so that it was not a totally unknown environment. The third person had requested that the second session of our interview not take place at the ABC center due to problems she was currently experiencing with other likely guests of the center at the time we had arranged. For her, the assurance of total privacy and her familiarity with some furnishings from the other building relocated there seemed to mitigate any disadvantage involved with the switch.

My biggest concern about the interviews in the planning stage was incurring a psychological threat to well-being for these consumers by bringing up painful or sad memories of the past. I was especially concerned about possibilities of an emotionally charged aftermath following the interview when we

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were no longer together. For this reason, I enumerated this as a potential threat on the recruitment tape and on the consent form to alert people to its possibility. After the session was over and the tape had been turned off, I talked informally to the person I was with, alert for any discomfiture or sudden shyness which might indicate an embarrassment at their disclosures to me. I had worked or interacted with most of the people prior to their volunteering for interviews, and felt that these informal assessments of how they were feeling about the process were accurate. When I did not know the person well or had mixed feelings about how they were reacting to the interview, I asked them directly what the experience had been like for them. Every person who interviewed with me had been more open and candid than I expected, and I believe that had they tried to hide their reactions it would have been readily apparent.

I learned a great deal about emotional resilience in the interviewing process and feel indebted to many of these people for insights I have gained in this regard. One woman, not well known to me, had shared many details of her 20 year history in the public mental health system with several mentions of family-based trauma as well. Clearly, there was pain and sadness associated with these memories. I was concerned that speaking of these things would lead to the emotionally charged aftermath I feared. But when I asked her about it, she laughed quietly and told me that these were old memories and since she lived through them when they happened, she certainly wasn't going to have problems with them that night!

Two other men, whom I had not met before, also shared some painful memories during their interviews. Both had openly cried during our meetings. When I asked how they felt at the end of the sessions, one of the men told me that he felt better for having cried, experiencing it as a cleansing relief. The other man, homeless at the time of the interview, and meeting most of his essential needs with money received for donating plasma, told me that he wasn't afraid of crying or feeling sad. He was afraid of hunger. Sadness was a "luxury" he rarely indulged in, and something he could handle. While these responses might arguably be attributed to a kind of false bravado, and/or a way of responding that would reassure <u>my</u> concerns, I experienced these communications as another instance of shared honesty, their "living truths," as it were. These comments, and others, helped me keep the interviews in perspective. They also intensified my wonder at the deep strengths in people whom I had thought so fragile.

The interview sessions were not without emotional respite. There were many opportunities to share laughter and/or poke fun at noted absurdities or strange contradictions discovered in consumer's ins and outs with the care system and the consumer organization over many years. I felt privileged that people volunteered for the interviews and were so open with me about their past, their present and their dreams for the future--when they had them. I felt enriched with each session shared.

I was surprised and frequently unprepared for the emo-

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tional aftermath *I* experienced after an interview had ended. Whenever a strong emotion was voiced by consumers during a session, my inner dictum was "let it be," and allow it to be expressed in ways most comfortable for the person, barring signs that they felt out of control with the experienced emotion. This never happened. Although I did not pretend to emotional neutrality during the interviews (nor do I think I could have, if I intended to), I was also aware that I did not give full vent to some feelings, particularly sadness, during the meetings. When they experienced sadness, I tried simply to be accepting of their need to express it, and neither add to it nor detract from it by reacting to it myself. What I learned during the months of interviewing, however, was that their sadness always registered at some level in my being and I sometimes found myself in tears as I drove home from a shared session or later, when I was transcribing a tape.

This is another reason why I do not believe that a "value-free" stance is possible nor appropriate for a project such as this. Stories of human pain, especially pain that might have been avoided or tended to in compassionate ways years ago, should evoke sadness--and anger--in other human beings. Such emotions fuel the fires of change (several U.S. civil rights movements demonstrate historical precedent for this truism). Self-reflexive methodologies that include strong emotion do connect to issues of transformative action, and a grounded critical theory can be its vehicle.

Data Analysis

In keeping with the methodologies that informed my research strategy, I used these data with nonstatistical content and inductive analysis procedures, similar to those used in more developed ethnographic studies. My 1983 field work and analysis for the final paper had proved the possibility of generating theory from data, in a "grounded theory" tradition. With this project, I wanted to raise that conceptual scheme a level higher. I hoped to increase the richness of a substantive grounded theory about these mental health consumers by developing a grounded theory that would complement extant theory in this substantive area. Hence, for the analyses on all ABC-related data, from 1983-1988, rigorous conventions applied to the "discovery of grounded theory" by its originators (Glaser and Strauss 1967) were used.

These "grounded theory" conventions included theoretical sampling, theoretical coding, theoretical "memoing," and generating theory that would provide a springboard for developing a "general substantive theory...more general than a substantive theory but not completely general as a formal theory" (Glaser 1978, 52). Glaser defines substantive and formal theories in this way:

> By *substantive theory* we mean theory developed for a substantive or empirical area of sociological inquiry --such as patient care, race relations, professional education, geriatric life styles, delinquency, or financial organizations. By *formal theory* we mean theory developed for a formal or conceptual area of sociological inquiry --such as status passage, stigma, deviant behavior, socialization, status congruency, authority and power, reward systems, organizations or organizational careers. Both types of theories may be considered 'middle-range.' They fall between the 'minor working

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> hypotheses' of everyday life and the 'all inclusive' grand theories (Glaser 1978, 144).

Through the vehicle of a general substantive theory, a formal, critical theory of mental health consumerism can be approached:

> If the focus of generality is on generating a formal theory, the comparative analysis is made among different kinds of substantive cases and their theories, which fall within the formal area, without relating the resulting theory back to any one particular substantive area (Glaser 1978, 145).

In this project, a grounded theory of mental health consumerism led to the beginnings of a general substantive theory of social vulnerability states. It meets the criteria for a general substantive theory (Glaser 1978, 52) in that its focus is on the substantive area, social vulnerability (common to the experience of mental health consumers participating in this study), but each case to which it applies is not a specific one, nor is its application so broad as to encompass all features inherent in the experience of comparative social disadvantage in everyday life. Below, I outline features of these research procedures which allowed this progression.

The key feature of theoretical sampling is that the "process of data collection is controlled by the emerging theory" (Glaser 1978, 36). The procedure specifically involves eliciting codes from raw data from the start of data collection through constant comparative analysis as the data accumulates. The coding categories direct further data collection which enhance the theoretical development of the codes, their various properties, and their connections to other codes. Data collection continues on these categories of codes until a

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category is "theoretically saturated," and additional data no longer enrich or expand the meanings that have emerged from the data collected thus far (Glaser 1978, 36-7).

Thus, theoretical sampling in this research project was constituted by original analysis of my 1983 field work and interviews which lead me back to the field for more observations (summer, 1986), then to a more hands-on position (employment at ABC), then to in-depth interviewing (in 1987 and 1988). The content of the interview guide was itself a product of these on-going, inductive analyses of accumulated data. By the time the interviews began, a winnowing of possible topics had occurred, allowing selection of questions in areas of known substantive and theoretical importance to this population.

Constant comparative analysis of all data collected between 1983-1988 informed the process of coding and recoding to generate substantive and theoretical codes. "Substantive codes conceptualize the empirical substance of the area of research. Theoretical codes conceptualize how the substantive codes may relate to each other as hypotheses to be integrated into a theory" (Glaser 1978, 55). For instance, one code identified early on, "ABC work," became differentiated into service work performed by participants (a substantive code) and "community maintenance activities" (a theoretical code).

A process of "open coding" each line of data (totaling over 73,000 lines) was followed to generate initial substantive codes. In this phase, "the goal of the analyst is to generate an emergent set of categories and their properties which fit, work and are relevant for integrating into a theory" (Glaser 1978, 56). During open coding, I also engaged in theoretical memoing ("the theorizing write-up of ideas about codes and their relationships as they strike the analyst while coding" Glaser 1978, 67), an invaluable aid for later generation of grounded theory. It was largely through appraisal of my theoretical memos that the latent (i.e., unintended and/or unacknowledged) consequences of ABC activities emerged as a feature of the grounded theory.

Selective coding followed. This refers to a refinement of coding to illuminate a core variable, and marks the end of open coding. "To selectively code for a core variable means that the analyst delimits his [her] coding to only those variables that relate to the core variable in sufficiently significant ways to be used in a parsimonious theory" (Glaser 1978, 61). It was through the process of selective coding that I identified "defining the situation" as the core variable in the field data. This emerged as a key feature in the work of the consumer organization and supports the (grounded) critical theory of consumerism developed from the data.

All coding activities were guided by the rules set forth for constant comparison analysis. The "basic, defining rule for the constant comparative method [is]: while coding an incident for a category, compare it with the previous incidents in the same and different groups coded in the category" (Glaser and Strauss 1967, 101). Four stages in the method are described by Glaser and Strauss (1967, 101-115): 1) comparing

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incidents applicable to each category, 2) integrating categories and their properties, 3) delimiting the theory, and 4) writing the theory. I will outline the application of stage one through three to the data.

Stage one, comparing incidents applicable to each category, involves coding each incident in the data into as many categories as possible. Categories themselves can emerge from the data or data can be coded into categories that "theoretical sensitivity" has led the researcher into constructing. "As categories and their properties emerge, the analyst will discover two kinds: those he [she] has constructed himself [herself]; ... and those that have been abstracted from the language of the research situation" (Glaser and Strauss 1967, 107).

For instance, I observed that volunteers for the organization, in particular, spent considerable time talking about their definitions of "ABC work," which necessitated developing a category for these mentions. I also observed a certain cadence in their description of people and events that were altered when they were recounting these descriptions to professionals versus other consumers. This seemed best captured by codes for "front stage talk" and "back stage talk," (concepts derived from Goffman's Stigma, 1963) which enhance the theoretical importance of the category "ABC work" without losing its substantive relevance as a grounded category.

Stage two, integrating categories and their properties, occurs over time. "As coding continues, the constant comparative units change from comparison of incident with incident to comparisons of incident with properties of the category that resulted from initial comparisons of incidents" (Glaser and Strauss 1967, 108). The best illustration for this comes from experiences with coding interview data.[1]

The "proxy" for incidents in the interview data were "social constructions of reality" (Berger and Luckmann 1967). I used this convention because it became apparent that the narratives that people offered could not be considered verifiable (i.e., I would not investigate the information they offered as part of their family background) and their depiction of family demographics, relationships, etc. was what they used to build subsequent understandings of people and events (e.g., "I couldn't work with that therapist because she treated me like my mother had"). Additionally, I found that interview data contained numerous instances of a step-wise progression of self-concepts that built on each other and culminated in descriptions of, for example, "self-as-mentally-ill."

This clearly echoed findings in a chapter entitled, "The Social Construction of a Crazy Reality," an ethnographic account of public mental health consumer experience developed by Estroff (1985, 213-239). Estroff had also applied similar sociology of knowledge logic to her findings. Thus, I adopted "social constructions" for a major category of analysis: it fit patterns found in data and was acknowledged as useful and

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[1] The authors note that researchers "may consider aggregates or single people as the equivalents of groups, with respect to strategies of comparative analysis" (Glaser & Strauss 1967, 47).

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Many items of discussion in the interviews could be coded as "constructions" of various types, which lead to sorting for several different social constructions codes (e.g., for hospitals, staff, family relations, self-concepts, etc.). Primary distinctions in the category emerged: self-constructions, relationship-constructions, and intersubjective constructions.

Self-constructions were comments aimed solely at understanding or describing the self without obvious use of other's ideas.[1] Relationship constructions were comments aimed at understanding or describing what this person thought entered into relationships: what was valuable, important, necessary, wrong, etc.. Intersubjective constructions were comments that indicated the person had developed her/his ideas about "X" based on other's ideas as well as his/her own, or referred to comments he/she made about "X" that revealed his/her idea about the nature of intersubjective reality. These distinctions were further refined into, for instance, self-constructions about him/herself as "sick" or "before sickness" or "after sickness," which allowed different themes concerning identity to emerge at the same time it allowed cross-comparison between interviews.

Stage three, delimiting the theory, is part of the process that occurs in stage two, but goes beyond these refine-

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[1] It was frequently apparent, however, that self-constructions unwittingly embodied communications of self received by mental health professionals.

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ments of category and property since it affects the emergent theory as well. For instance, role-bridging, the apparent core variable in the field data when I first analyzed them in 1983, explained much of the work that Ashton did, but it did not encompass the work of many other volunteers or staff and it did not explain why people who did not know Ashton used the services of the organization on a continuing basis. Over time, the concept no longer seemed to "fit" the data. The "role-bridging" processes seemed better applied to a category developed to accommodate data accumulated by 1988: "definitional work," i.e., work that was purposefully directed to providing a definition of the situation or altering a definition of the situation (for a particular consumer or, frequently, for mental health providers seeking advice).

As seen in this example, delimiting allows the integration of more details and reduces underlying uniformities in the original set of categories or their properties, allowing the formulation of theory with a smaller set of higher level concepts (Glaser and Strauss 1967, 11).

The delimiting process also forces a reduction in the original categories of coding. Thus, within the "definitional work" category, sub-categories of intersubjective constructions and relationship constructions emerge, allowing refinements in an otherwise unwieldy category "ABC work." Another important factor that delimits the list of categories is that they become "theoretically saturated." This occurs when incidents are encountered in the data that simply add bulk, but no theoretical import, to the nascent theory.

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Although all the social construction categories I developed did become theoretically saturated, I continued to code each incidence of their use because the <u>number</u> of mentions in certain categories emerged as a salient factor in consumers' conception of self as primarily "mental patient" or "consumer advocate," despite some overlap between these social identities. By counting the frequency of codes[1] such as "self-construction, sick" and "hospitalization construction, positive" (among others), the relation between positive regard of hospitalizations, predominant use of "self-construction, sick" references, and a "mental patient" primary identity became apparent. Similar frequency counts of codes for experiences at ABC, combined with other interview content analyses, alerted me to ways in which participants constructed a self-identity specific to the ABC community.

<u>Research Sample Characteristics</u>

The interview sample was chosen according to the conventions of "theoretical sampling," i.e., sampling done to generate theory (see Glaser and Strauss 1967, 61-69; Glaser 1978, 45-77). The substantive theory of focal concern applies only

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[1] "If the analyst's purpose, besides developing theory, is also to count incidents for a category to establish provisional proofs then he [sic] must code the incident. Furthermore, Merton has made the additional point...that to count for establishing provisional proofs may also feed back to the developing theory, since frequency and cross-tabulation of frequencies can also generate new theoretical ideas" (Glaser and Strauss 1967, 111). Merton's comment captures what occurred by counting frequencies, i.e., generation of a new part of the emerging theory.

to mental health consumers using the organization, Alternatives By Consumers (ABC). Thus, to generate categories and properties of categories that allowed themes for theory in this substantive area to emerge, only consumers participating in the organization were solicited.

The intent was not to achieve full statistical coverage of the population "mental health consumers." Thus, the sample is not representative of mental health consumers of the U.S., nor of the state of Michigan, and may not generalize to all consumers who use the Alternatives By Consumers organization. However, the sample may be typical of consumers who become <u>involved</u> in operations of consumer-run organizations, particularly since each person who participated in the interviews elected to do so.[1] As these organizations proliferate (as they have during the 1980s), analysis of these data may yield important insight into questions concerning likely participants and/or likely benefits gained by participants in other consumer-run organizations in other areas of this state or elsewhere in the U.S.

Assessing the accumulated data at the end of the ninth interview, it was clear that I was already approaching "theoretical saturation" in many of the categories of interest (i.e., in categories discovered through coding field notes and earlier interviews by inductive analysis). Glaser defines theoretical saturation of a category in this way:

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[1] The issues of research bias and self-selection of interview participants is addressed in the preceding "Recruitment Procedures" section of this chapter.

> [This] occurs when in coding and analyzing both no new properties emerge and the same properties continually emerge as one goes through the full extent of the data (Glaser 1978, 53).

I determined that the analytical divisions I had supposed would apply to the data, such as ABC employee versus volunteer versus service recipient versus guest-only statuses, were not distinct. Moreover, were I to "correct" for the self-selection bias I found (i.e., disproportionate numbers of Caucasian women) and recruit more participants for interviews, time constraints would preclude line-by-line analysis of the additional data.

Thus, within this context, I decided that 15 interviews would suffice for this study. I felt I had acquired sufficient data to constitute a viable theoretical sample. "Theoretical sampling on any code ceases when it is saturated, elaborated and integrated into the emerging theory" (Glaser 1978, 36).

Table 1 (following) provides a summary of the sample demographic data (i.e., age, education, racial or ethnic affiliation, gender). Of the fifteen people who participated in interviews, four are men. Two of the four men are also Viet Nam veterans, drafted in their teens. The median age for the sample is 29.6 years, with a range of 22 to 48 years. Eighty per cent of the respondents defined themselves as "Caucasian" or "white." The ethnic and racial mix is represented by three women who defined themselves as "black," "mulatto," and "Puerto Rican," respectively.

All persons in the sample attained a minimum of a high school degree or its equivalent. Thirty-three per cent (5

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people) have gone beyond high school: one woman received an associate baccalaureate degree from a community college in video production technology; another woman is a registered nurse with additional credentials in substance abuse and chemical dependency counseling; one woman and one man graduated with a B.A. in psychology; and another woman was only weeks away from receiving her B.A. in humanities from Michigan State University when we interviewed together, so she is listed as having received it in the table.

Table 1: Summary Demographic Data

Age Ranges	Education	Race	Gender
22-29 = 5	1-12 years = 9 (H.S./GED)	White = 12	Women =11
30-39 = 6	13-14 years = 2 (R.N./A.B.)	Black = 1	Men = 4
40-48 = 4	15-16 years = 4 (B.A.)	Other = 2*	(N =15)

* Other = Puerto Rican, Mulatto

As seen in Table 2 (following), slightly over half the sample (53%) are single and have never been married. Two of these single women have one child; one of the two is living with her infant son. The other woman's son is grown and living elsewhere. Thirty-three per cent are divorced (4 out of 15) or separated (1 out of 15), and two people have divorced twice. Several of the divorcees have children that they visit or who come to visit them, but only one woman has custody of her minor son whose residence in her home is an on-again, off-again affair. One man became a widower after his return from

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Viet Nam when a tragic accident fatally injured his young daughter and wife. Only one person in the sample is currently married (his only marriage) and living with his wife and children.

Table 2: Summary Marital Status

Marital Status	Women	Men	Totals
Single (never married)	7	1	8
Married	0	1	1
Separated (not divorced)	1	0	1
Divorced (once)	2	0	2
Divorced (twice)	1	1	2
Widowed	0	1	1
Totals	11	4	15

In the following Table 3, details on family of origin birth order, and changes in sibling age-ordering due to remarriage and/or out-family placement at early ages (i.e., before 6 years of age) are noted. Included are data on the number of siblings in the home in which sample participants were raised, with their birth order in the family shown in the next column. It is remarkable that the mean number of siblings is 4.8 per interview volunteer, as this well exceeds national census figures for average number of siblings in U.S. families.[1] Only one man was the sole child in his family. In the three cases where the rank ordering of children in the home was altered by

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[1] Additionally, birth order and number of siblings in the family are often noted as important psychosocial variables with respect to subsequent emotional development in adolescence and adulthood.

remarriage and/or out-family adoption, the changed sibling age-ordering is shown as well. It is striking that the only two persons who were first born in their family of origin (which is often noted as a positive factor in mentally healthy development) both lost this status during early childhood due to remarriage(s) of their parents. The other change in family age ranking of children occurred when one young woman was given up for adoption by her natural parents at the age of 4 years and went from the youngest of two children in her original family to the youngest of three children in the adopted family.

Table 3: Summary Birth Order

Number of Siblings	Family of Origin	Changed* Order
None = 1	Only = 1	Only = 1
1-2 = 1	Eldest = 2	Eldest = 0
3-4 = 3	2 or 3 = 8	2 or 3 =10
5-6 = 6	4 or 5 = 2	4 or 5 = 2
7 = 4	6 = 2	6 = 2
Mean # = 4.8	Youngest = 0	Youngest = 0

* Due to parent(s) remarriage(s) and out-family adoption or foster care placement (age 7 or younger)

Most of the people in this sample came from working class homes, i.e., the father (or male guardian/caretaker) engaged in manual occupations and the mother (or female guardian/caretaker) worked inside the home or on a part-time basis in a non

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non-professional occupation.[1] Only one man came from a home where both parents were professionals in the health care field. Four people came from homes where one or both of the primary caretakers completed college. One woman's father had also completed a Ph.D.

The next two tables indicate "Disability Benefits History" (Table 4) and "Income Sources at the Time of Interview" (Table 5), factors which emerged as significant to "mental pa tient" versus "consumer advocate" career trajectories. (Full discussion of the significance of these factors appear in following data analysis chapters.) Two people in the sample had never received governmental benefits, one of whom worked full-time as a nurse, and another worked part-time while living in her mother and step-father's home as she attended college. This same person had previously worked full-time at Alternatives By Consumers before returning to school. Two other women had received only Aid to Families with Dependent Children (AFDC) benefits, but none for psychiatric ailments. Of the remainder, eleven of the thirteen (73% of the sample) were currently or had previously received benefits tied to their psychiatric histories. Ten of the eleven had received/were receiving benefits that constituted their only source of income. This came in the form of social security disability (SSD) payments if the person had held competitive

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[1] This sample finding accurately reflects the social class-of-origin for the majority of people participating in the ABC organization. I judge this on the basis of observation and knowledge about participants gained while an employee of the organization.

employment, and social security supplemental income (SSI) payments if they had not. The length of time people received benefits had a wide range, from less than six months to more than six years. At the time of the interview, six people (40% of the sample) were supporting themselves in competitive employment, including the current employees of the organization. Two of these six also supported dependents, and had annual incomes at or near $24,000. The other four people who were employed and supporting themselves had annual incomes that ranged from $13,000 to $10,000.

Table 4: Disability Benefits History

Disability Income History (in Years)	Source SSI	SSD	Both
Less than 1 yr = 2	1	1	0
1-2 years = 2	1	1	0
2-3 years = 5	3	2	0
3-4 years = 1	1	0	0
Over 6 years = 1	0	0	1
Totals N =11	6	4	1

Table 5: Income Sources at Time of Interview

Gender	Full-time Employment			Part-time Employment			Disability Only		No Income Source	Totals
	sole	+SSI	+SSD	sole	+ SSI	+SSD	SSI	SSD		
Women	2	1	1	2	0	1	3	1	0	11
Men	1	0	0	0	0	1	1	0	1	4
Totals	3	1	1	2	0	2	4	1	1	15

Since the occupational situations for most people who volunteered for interviews are directly tied to their "mental patient careers," I have also included these data as sample characteristics. Table 6, below, details psychiatric hospitalization data for people participating in the interviews. Included in the table are columns denoting total number of hospitalizations for psychiatric reasons; the range of years during which hospitalizations occurred (which I have labeled "inpatient career years"), for which the first hospital admission date and most recent admission dates were used; and a final column showing years since last hospital admission (including a category for less than 1 year).

Table 6: Summary Psychiatric Hospitalization Data

Total Number of Hospitalizations (N=15)	Inpatient "career" years:span between 1st & most recent	Years since last admission (Range)
None = 1	1 yr or less = 4	Less than 1 = 6
1--3 = 2	4--7 years = 3	2--3 years = 4
4--9 = 9	10-23 years = 6	5-10 years = 3
10-16 = 3	32 years = 1	Over 24 yrs = 1

Table 7 (below) summarizes hospitalization data, providing a breakdown by age at first admission (before or after 18 years of age) and gender.

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Table 7: Summary Hospitalization Data by Age and Gender

Gender	Any Hospital First Admission		Totals Any Hospital
	Adult	Youth	
Women	5	5	10
Men	3	1	4
Totals	8	6	14

Table 8, following, expands the detail of summary hospitalization data, noting gender, and age at first admission to a state mental institution (when applicable). This is included because inpatient care received in state institutions was also found to contribute to subsequent mental health care patterns for involved ABC participants. Although there was one exception to the general finding, early hospitalization in state facilities lead to numerous hospitalizations in local, community-based hospitals.

Table 8: State Hospitalization Data by Age and Gender

Gender	State Hospital Admission		Totals State Hospital
	Adult	Youth	
Women	5	4	9
Men	2	1	3
Totals	7	5	12

An overview of hospitalization data indicates that the median number of psychiatric hospitalizations for sample members is 5.53, which includes one woman with no past inpatient history. The range of years during which inpatient care was received was from 1955 through December, 1987. Several people had fairly recent experience with hospitalization, but two people, hospitalized only when adults, had been without inpatient care for nearly ten years.

It was not possible to determine a mean length of hospital stay because recall of such detail in the context of multiple admissions was difficult. However, a notable pattern was that the longest incarceration occurred when people received inpatient care as children or teens, which applied to forty per cent (6 people) in the sample. Interestingly, people having this experience could usually recall the precise number of days for those hospitalizations. The shortest stay for a child or adolescent admission was 45 days, and the longest was 480 days (16 months).

Hospital days accrued as adults varied considerably. In no case were people admitted for less than a week. If they had been committed for treatment to the hospital, their stays were usually 30 days at least; if they had gone to the hospital for a detoxification program connected to alcohol or substance abuse, those stays were 28 days. Three people, two men and one woman, had participated in such a program for at least one, but not more than two, of their hospitalizations. Only one woman hospitalized as a teenager did not have adult inpatient psychiatric history.

Sixty per cent of the consumers interviewed had received inpatient care in a state mental institution (9 out of 15); thirty-three per cent (5 people) had been inpatients before age 18, and two of these five had also been in state hospitals as adults.

The final sample data summary chart (Table 9, following) details salient factors in participants' involvement with the consumer organization: their length of contact with ABC is cross-referenced by gender and level of involvement, shown in the table as "high," "moderate," or "low."

Table 9: Alternatives By Consumers Participation Summary Data

Length of Contact	Women			Men			Totals
	High	Mod.	Low	High	Mod.	Low	
1-2 years	1	2	1	0	1	1	6
3-4 years	1	0	1	0	0	0	2
5-8 years	4	1	0	1	1	0	7
Totals	6	3	2	1	2	1	15

Three people have been involved with the organization for eight years, since 1979 when it was first organized. Other sample members indicate their first contact was made six years ago (1 person), five years ago (three people), two or three years ago (1 person, respectively), and the modal grouping is found to have made contact less than two years before the interview occurred (forty per cent of the sample). Sixty per cent of those interviewed intentionally ended, then later rekindled, contact with ABC after their initiation to it, and yet only one of these people did not serve as a volunteer for the organization. Most people had been volunteers, with only two people (13%) indicating that they hadn't been. Four people with whom I interviewed were current employees of the organization, and an additional person in the sample had previously been employed there.

Most people had a characteristic pattern of involvement (i.e., high, moderate, or low) with the organization. These patterns of involvement were determined by assessing: length of contact with the organization; formal position within ABC (e.g., staff, Board of Directors' member); volunteer activity for the organization, noting number of volunteer hours worked in an average week, and the kinds of tasks pursued, on or off-site; number of weekly visits to ABC and activities pursued during visits; participation in social events at ABC (parties, holiday meals, support meetings); participation in advocacy events (ABC-related presentations made in community or other forum); submission of material to ABC newsletter; and expressed commitment to the ideals of the organization (as participants defined them). Not surprisingly, all of ABC's current or past full-time employees were in the "high" range of involvement, as was the person paid for cleaning services to the organization for four hours each week. Several ABC volunteers were also included in the "high" involvement category. (These ABC involvement patterns will be examined again in Chapter 7.)

The next two chapters present the case study of the organization. Chapter 4 constitutes "Part I: Historical context and Emergence of a Leader." Chapter 5 constitutes "Part II: Natural History of ABC, A Stage Analysis." As a whole, the case study examines the creation and evolution of Alternatives By Consumers, with attention to the import of its development and growth for ABC participants, the community, and the larger mental health care system.

PART II

Case Study

Chapter 4 - Case Study of the Organization, Part I Historical Context and Emergence of a Leader

Chapter 5 - Case Study of the Organization, Part II Natural History of Alternatives By Consumers: A Stage Analysis

CHAPTER 4

CASE STUDY OF THE CONSUMER ORGANIZATION, PART I: HISTORICAL CONTEXT AND EMERGENCE OF A LEADER

Introduction

The case study of Alternatives By Consumers (ABC) describes the natural history of the organization over time, in two parts (Chapter 4 and 5). The historical context of events occurring in the realm of mental health care introduces the case study discussion in this chapter. This situates case study data in culturally relative time and space. The practice of deinstitutionalization in the U.S. during the late 1970s was unlike deinstitutionalization practice in other areas of the Western world. The 'social space' of this same period in the U.S. was also culturally unique relative to other Western countries: it was a time of wide-spread interest in civil rights issues. This wave of interest was part of the impetus for special attention to mental patients' rights. The emergence of the first ABC leader, and the founding of the organization shortly thereafter, were not happenstance; these events are best conceptualized as by-products of this unique period in U.S. social history.

An overview of the Mauss (1975) theoretical model of "social problem-movements," following the discussion of historical context, provides a framework for assessing congruence between the model and the actual events of ABC's evolution (depicted in Chapter 5). I frame the discussion according to the tenets in the social problem-movement model because Mauss' theory was derived from many other social problem <u>and</u> social movement theories. As such, it represents a cogent synthesis of the dominant ideas in both of these literature categories. Thus, the strengths and weaknesses in the applicability of the Mauss model to this organization's history largely represent a condensed discussion of the applicability of social problem and social movement literature to workings of this mental health consumer-run organization.

Because the inception and growth of ABC is entwined with the mental health care experiences of its founder, Steven Ashton, his role as "champion" of the Alternatives By Consumers organization/ "social-problem movement" is also considered in this chapter. The term "champion" is used by Mauss (1975) to refer to people crucially involved in the development of a "social-problem-movement." Mauss conceptualizes social movements as collective efforts which generate social problems, asserting that both share characteristic patterns of development and dissolution over time. Champions of social movements are seen as generating social problems by their efforts. The applicability of this latter conceptualization to Ashton's role for the ABC organization is assessed in the discussion.

Ashton's mental health care experiences are also important because there is considerable overlap between his experiences and those of most consumers of public mental health care. Parallels to and departures from a typical public consumer trajectory are noted throughout the discussion. Significantly, Ashton's experiences reveal how layers of social vulnerability accumulate for many mental health consumers. A unique twist in his experiences, access to a program previously available to public consumers in the mental health system, illuminates the possibility of structuring programs that can provide release from some aspects of social vulnerability. Attenuation of Ashton's coping difficulties through participation in the program simultaneously provided passageway for his organizing efforts; the beginnings of the ABC "social problem-movement."

In the second part of the Case Study (Chapter 5, following), tensions are revealed as Mauss' (1975) theoretical stage analysis is applied to ABC's history. The chronology of events in ABC's evolution are appraised, first within boundaries of the Mauss model, and then from a variety of other theoretical vantage points that enlarge our understanding of this group.

I conclude the first part of the case study in this chapter by briefly considering the possibility that ABC represents a "social-problem-movement." This discourse alerts the reader to tensions in the _practical_ application of a _theoretical_ model to these data, which continue as the Mauss model is applied to the natural history of ABC in the following chapter.

Deinstitutionalization and Mental Patients' Rights

A number of events in the 1960s and 1970s contributed to important changes in the social climate of the U.S. The ascendancy of civil rights issues called forth a number of efforts to identify and ameliorate social conditions deemed problematic by members of a concerned public. Among the social problems attracting attention were treatment issues for persons labeled "mentally ill." One issue that was to have profound impact on subsequent mental health treatment was deinstitutionalization. This policy, in turn, focused widespread attention not only on treatment issues that became more visible in community settings, but also on issues of mental patients' rights.

Efforts to enact a national "deinstitutionalization" policy were fueled by a number of different interests. The original idea behind deinstitutionalization was stipulated in functional terms, i.e., the community was to provide the asylum heretofore accorded by incarceration in state hospitals. To do so, patient populations in state hospitals were to be drastically reduced, and community mental health care was to be developed then implemented, subsidized with federal funds. Coordination efforts would be under the auspices of the National Institute of Mental Health. The need for a federal mandate to provide these community services echoed the civil libertarian ethos of the time: the federal government had to set certain national standards of treatment to protect citizens in less enlightened states. Although deinstitutionalization is not a treatment for emotional problems per se, its implementation paved the way for the development of community-based mental health care services.

Deinstitutionalization practice has been defended as the means by which iatrogenic effects of hospitalization (e.g., institutionalization or the "institutionalization syndrome") would be reduced or eliminated by providing a more "normalized" and less restrictive living situation in the community (Bloom 1984). The network of Community Mental Health Centers would provide aftercare to ease the transition from state hospital discharge to community living and/or preclude the need for hospitalization entirely, regardless of the severity of the coping problems people experienced.

Deinstitutionalization has been characterized as an "accumulation of ad hoc decisions" representing a "failure in public policy" (Lerman 1982, 216). Others term deinstitutionalization "policy"[a] and subsequent community-based program development a failure (Hill 1983; Rhoden 1982; Rochefort 1984) or a sham (Walsh 1984).[b] Scholars and lay critics alike have noted connections between deinstitutionalization, deficits in community aftercare offerings, and increased numbers of homeless persons on U.S. streets (Halpern et al. 1980; Hartman 1985; Hombs and Snyder 1982; Hopper 1982; Lerman 1982; Nelson 1985; Stallard et al. 1983; Walsh 1985). In the context of deinstitutionalization, "the concept of Community Mental Health Centers implied ... a promise: treatment and rehabilitation of the severely mentally ill within the community" (Bassuk and Gerson 1978, 47).

The promise that deinstitutionalization held for psychiatric hospital patients who were returned to community settings for treatment has largely faded (Bassuk and Gerson 1978; Friedman 1983; Rosenzweig 1983; Pepper and Ryglewicz 1982; Brown 1979). Some hope future reform in deinstitutionalization practice will usher in a new era of mental health treatment (Department of Health and Human Services 1980; Talbott 1984), but their hope for reform belies its failed promise.

The experience with deinstitutionalization practice in the United States stands in stark contrast to the experience in northern European countries. There, severe labor shortages after World War II gave impetus to immediate development of innovative and successful vocational rehabilitation programs for previously institutionalized persons, whose labor was in demand (Warner 1985, 92). In the U.S., there was no labor shortage following World War II, and means of subsistence (i.e., through disability benefits and federal health insurance) were not provided for those leaving institutions until 1965. Moreover, as successful rehabilitation and development of non-institutional aftercare plans preceded the wide-spread use of psychiatric drugs in northern Europe, the drugs were not linked to release from the institutions (Warner 1985, 93) as they have been in the U.S.. In Great Britain, for example, psychiatric drugs were found to be effective only in treatment settings marked by a <u>lack</u> of rehabilitative efforts (Rathod [1958] in Warner 1985, 86).

Warner has argued that the absence of a labor demand in the U.S. during the post-war era delayed the development of truly rehabilitative community-based mental health care (Warner 1985, 99). Delay in this area resulted in the introduction of psychotropic medications when many long-term psychiatric patients were still in state hospitals where custodial care was the norm. Because the settings were inadequate and non-therapeutic, psychotropic medications seemed to be an effective treatment (Warner 1985, 82-87). At this juncture, deinstitutionalization proponents in the U.S. came to believe that psychotropic drug administration was necessary for community care. This erroneous interpretation would later fuel support for mental patients' rights.

Although deinstitutionalization was proposed as early as 1955 in the States, the movement toward enactment of the policy only escalated after the passage of the Community Mental Health Centers Act (1963) which funded development of a nation-wide network of Community Mental Health Centers where community based services, geared toward prevention, education, early treatment and crisis intervention would be provided. Start-up funds for the CMHC Act were allocated in 1965, the same year that Congress passed the Medicaid/Medicare bill. This bill permitted people with no promise of employment access to a means of subsistence, including funds for housing in nursing and boarding homes and payment of psychiatric medication costs. Thus, the belief in the effectiveness of psychotropic medications followed discharged patients to the community.

It was the advent of the antipsychotic drugs, facilitating

> control of the florid features of patients' psychosis even when the patients are in grossly inadequate settings, which allowed huge numbers of the mentally ill to be shunted to cheaper nursing home care (Warner 1985, 87).

Deinstitutionalization allowed expatients of state and community hospitals to meet in community settings with other mental health consumers who were receiving services. In this gathering, they exchanged tales about their treatment experiences. To tell the story of one's pain, in the presence of supportive peers, gives voice to some who would otherwise not be heard and affirms the worth of the person struggling with community living problems. Telling the story is the beginning of the healing process--it is a path to new horizons as well, where received prognoses (such as "mentally ill" for life) are over-turned and new hope is birthed. The narrative of the "survivor" bears witness to struggles that secure hope in life. As Myerhoff found in her study of elderly Jewish people in an urban ghetto,

> The tale certifies the fact of being and gives sense at the same time. If none listen, nevertheless the tale is told aloud, to oneself, to prove that there is existence, to tame the chaos of the world, to give meaning (Myerhoff 1978, 271).

These shared narrations among expatients constituted the first step toward eventual empowerment, self-advocacy skill development, and an interest in securing civil rights, in or out of treatment institutions. In this interest, they joined growing ranks of supporters advocating for patients' rights.

While analytical distinctions are frequently blurred by multiple loyalties, players in the patients' rights arena can be grouped according to organizing rationales. The dominant divisions were represented by adherents of a critical rationale; a humanitarian rationale; a community psychiatry rationale; a cost rationale; and an experiential rationale. Whatever their vantage point, this combination of interests led to change in the mental health system:

> [A] range of legislative, judicial and administrative changes in patients' rights have greatly affected recent psychiatric care. These include: due process in commitment hearings, a preference for voluntary rather than involuntary commitment, the attempt to provide treatment in the 'least restrictive environment,' the abolition of compulsory patient labor, the right to treatment (i.e., the state's responsibility to provide therapeutic and/or rehabilitative treatment rather than merely custodial care), the right to refuse treatment (e.g., psychosurgery, electroshock therapy, chemotherapy, restraint, seclusion), various safeguards for hospital procedures, and granting of civil rights, such as the right to contract, vote, and hold licenses (Brown 1985, 174).

These changes can be credited to the variety of actions pursued by supporters of the organizing rationales noted above. Because many of these rationales continue to affect advocacy efforts, an overview of each area's membership and their respective effect on patients' rights issues reveals historical and contemporary dynamics with which consumer groups like Alternatives By Consumers must still contend.

Supporters of the critical rationale developed an interest in patients' rights as an outgrowth of their severe criticisms of psychiatric treatments and the medical model of "mental illness." Collectively termed "antipsychiatry" (Brown 1985, 167ff) by some or "the critical wave" (Manning 1976, 43ff) by others, proponents of psychiatric critique have included psychiatrists (e.g., R.D. Laing (1959, 1965, 1963, 1967), David Cooper (1967), Thomas Szasz (1963, 1970)); sociologists (e.g., Faris and Dunham (1939), Hollingshead and Redlich (1958), Leighton (1959, 1963), Frank (1961)); labeling theorists (e.g., Lemert (1951), Goffman (1961, 1971), Scheff (1966, 1974)); existential phenomenologists (e.g., Ludwig Binswager (1963)); activist scholars in the U.S. (e.g., Bramel and Friend, 1982); and a variety of nonmainstream representatives (e.g., feminist therapists, gay and lesbian therapists, radical therapists, "alternative free clinics" counselors). Phil Brown summarizes the effect of antipsychiatry and its connection to the institutional reforms pursued by patients' rights organizers:

> These parts of antipsychiatry...mainly affected private practice of psychotherapy for relatively undisturbed people, and became part of a general progressive social and cultural awareness. By this influence, antipsychiatry paved the way for acceptance of the mental patients' rights movement by more sectors than might otherwise be supportive of the movement (Brown 1985, 172).

As the ineffectiveness of traditional approaches to psychotherapy were revealed, and merged with findings of class, sex and race bias found in treatment practices, other groups were attracted to issues of patients' rights from a humanitarian viewpoint.

An important caveat should be noted before examining the humanitarian viewpoint. The "[mental health care] system wishes to preserve its self-proclaimed humanitarian impulses" (Brown 1985, 174) as the dominant impulse for the ascension of patients' rights in the deinstitutionalization era. However, Warner argues that a philosophy of care is probably shaped more by contemporary patterns of institutional use rather than concern for welfare, liberty and human rights of the institutional inmates which might outweigh the fear of their liability to the community:

> Humanitarian concerns, while usually part of the rhetoric associated with changes in institutional use, are probably never sufficient cause for such changes. They can scarcely account for the widespread current practice of maintaining psychotics in poverty, housed in degrading environments in the community, largely without proper care and treatment (Warner 1985, 91).

Early supporters of a humanitarian rationale for patients' rights were comprised of civil libertarians and members of the general public whose concern for civil rights dominated the social climate of the U.S. during the 1960s and 1970s. The constituency of humanitarian supporters for patients' rights also included: sympathetic judges, attorneys pursuing litigation on behalf of patients' and/or their families, voluntary associations concerned with treatment and rights issues, and former hospital workers.

Civil libertarians can be further delineated by the type of advocacy group (Freddolino 1983) and the thrust of their support efforts. Drawing on Freddolino's typology, Brown (1985, 202) suggests division into two focal camps: "supportive advocacy" (i.e., advocating for service provision or reforms on a case-by-case basis) or "representational advocacy" (i.e., advocating for changes, improvements, or development of policies affecting the population of mental health consumers).

Most of the contributions to patients' rights issues from supporters of cost and community psychiatry rationales came through the vehicle of deinstitutionalization. Sympathizers with institutional reform cited rising costs of state mental hospital care on the one hand the intolerable conditions raging within them on the other.

> To the extent that anticustodialism criticizes the abuses committed against individuals, it also emphasizes their human rights. In this sense, the critique of custodial institutionalization often leads to support of some degree of patients' rights. (Brown 1985, 174-5).

Because the costs of physical plant renovation, rehabilitative program development and increased staffing for state institutions were too high to be borne by individual states, there was movement toward release of responsibility for state hospitals through deinstitutionalization and embrace of the idea behind community psychiatry, i.e., community-based care subsidized with federal funds.

With community psychiatry's mixed loyalties to a bureaucratically administered mental health care system, to professionalist psychiatric ideology, and to the well-being of individual patients, it is not surprising that support for deinstitutionalization, by fiat, brought support for civil rights of the mental health consumer in its wake.

> There is a strong indication that resistance to patients' rights may be structurally inherent in the system of inpatient mental health treatment, whereas in a shift to outpatient care as the norm, staff would have less need to control patients in an all-encompassing manner (Freddolino [1982] in Brown 1985, 187).

Arguably, the most important organizing rationale that impelled movement toward patients' rights was direct experience with mental health treatment practices. As Brown notes,

> Much of the success of patients' rights issues has been due to the organizational efforts of patients' rights groups....Small groups of expatients began to assert their

> anger at being committed for what they saw as minor deviant acts, and then being resocialized into an institutional life style...They also organized through publications, news conferences, and forums to oppose psychosurgery, electroshock, aversion therapy, and prison behavior modification programs... (Brown 1985, 174-5).

This recitation does not exhaust the treatment reform issues for which expatients and other mental health consumers advocate. Administration of psychotropic medications in excess is a volatile issue, as are continuing problems with access to affordable and safe housing and the implementation of genuinely rehabilitative programs and/or therapies.

Other consumer groups, composed of expatients and users of community outpatient programs and therapies, fall into the second of two advocacy categories defined by Wald and Freidman (1979). The first type, "civil libertarian" advocates, concentrate energies on prevention of intrusive treatment procedures and deprivation of liberty by commitment. The second category describes the work of many mental health consumers, "service oriented advocates." They "want the right to treatment expanded, and feel that commitment is all right if treatment is provided" (in Brown 1985, 202-3).

Categorical definition as "service oriented advocates" does not subsume all of the goals pursued by the "consumer-run alternative service" organization, Alternatives By Consumers (ABC). However, it does give an inkling of some of the efforts they have undertaken in the community for, and with, their peers in the mental health system. Largely, their work defies ready categorization: they seek to attain specific objectives with some individuals and philosophical enlightenment for many. Conceived in the era of deinstitutionalization and guided by experiential insight, they are champions of patients' rights.

The Theoretical Model, Social Problem-Movements

The theoretical model of "social problem-movements" outlined by Mauss (1975) "rests upon the proposition that the characteristics of social problems are typically also those of social movements" (Mauss 1975, 38). The shared characteristics include subjective definitions of reality, formation of interests groups with their respective constructions of reality, the efforts of such groups to mobilize public opinion, and others processes typical of collective behavior and social movements. The importance of subjective constructions of reality versus objective social conditions are revealed in culturally relative perceptions that determine what is a social problem, the insufficiency of objective social conditions to produce social problems in and of themselves, and the unpredictability of social problems developing from any one set of social conditions (Mauss 1975, 37-8).

Mauss asserts that specific social movements follow on the heels of general movements and customarily have a temporal career dimension. Focused on conditions defined by a concerned public as a social problem, over time the specific social movement actors interact in patterns typical of informal and/or formal organizations.[c]

Typically, the structural characteristics of social problem-movements manifest interaction patterns occurring within three "rings." The outer ring is comprised of a concerned public "whose sympathies definitely lean in the direction of a particular movement's ideology or program" (Mauss 1975, 47). They are frequently a source of financial support and other valuable resources and by sheer weight of numbers add to the political strength of a movement.

The second ring is comprised of people and organizations active in the interests of the movement, but "not necessarily focused exclusively on the movement." Considered members of the movement, they are often skilled in organizational behavior (e.g., committee work) and frequently lend the movement a certain legitimacy.

The innermost ring of the movement is the "heart or core." "It contains the principal leaders and the organizations having their goals exclusively in the success of the movement" (Mauss 1975, 47). "Champions" of the social-problem movement are found in this inner most ring.

The natural history of a social problem-movement is dependent on the nature of the interaction with the society that produces it (the host). The evolution through which it passes can be depicted in five stages whose dynamics are rooted in the interactive effects between the movement membership and the host society. The interactions are characterized by the movement's attempts to accommodate demands and strains caused by its relation to the host society while expanding its membership base and maintaining its goal-directed behaviors. At the same time, the host society responds through its dominant institutions (e.g., government, family, church, business) in generally resistive and predictable ways. Generalized inertia, apathy or hostility in the host institutions is par when the traditional definitions of consensual reality are challenged by a social movement. Thus, the two primary responses from the host society are efforts to coopt or repress the membership of the movement.

In terms of this model, cooptation refers to ameliorative gestures in the direction of meeting and neutralizing the movement's criticisms, combined with propaganda effort emphasizing those interests and values which the society shares with the reform movement. Repression refers to social control techniques on a continuum from direct police action to ridicule occurring across all institutions of society. The society's "precarious balance" vis-a-vis the movement is a mix of repression and cooptation since the movement is challenging the consensual reality definitions that maintain social order. The movement's "precarious balance" vis-a-vis the society is a mix of power or oblivion. "The fortunes of the movement are thus determined in large part by the particular mixture of cooptation and repression applied by the society and by its own manipulation of, and responses to, that mixture" (Mauss 1975, 61).

Over time, these responses change to meet the counter-response posed by the movement, yielding societal shift in emphases during successive stages, first toward cooptation and later toward repression as the movement experiences its career trajectory, formed in the interplay between actors of social institutions and the movement. Stages in the interaction between the movement and its host society include: incipiency, coalescence, institutionalization, fragmentation and demise.

The incipiency stage is characterized by groping, uncoordinated efforts to address a problem around which people have gathered in sympathy. There is no established leadership or membership, but there is a concerned public whose interests are threatened by what they consensually define as a social problem. This is the time during which the outer most ring in the model is formed, and the activities occurring within it include ad hoc meetings among people sharing focal concerns, letter writing to congresspeople and editorial staff on local papers, etc., offering definition of the problem and solutions or resolutions of it.

The societal response at the incipiency stage is mostly cooptative. Little repression is directed toward the movement since its challenge has not yet gained sufficient power to present an actual threat to the traditional ordering of dominant social institutions. This cooptive effort by the host society evokes a counter-response in movement actors. It is now important to establish clear boundaries between definitions of the problem offered by the movement and definitions offered by the host society. The search for a movement identity is inspired by societal efforts to neutralize the criticisms that have been voiced. Additionally, defenders of traditional definitions of social reality may engage in propaganda efforts to enhance movement sympathizer's awareness of interests and values that are shared, de-emphasizing interests or values that are at odds.

Stage two is an outgrowth of these first unfocused efforts at reform by the movement. It is a period of coalescence, which allows the formation of the two inner rings in the model. Formal and informal organizations arise from members of the concerned public. These developments are seen as a response to provocative acts and/or disappointments from failures of the traditional system to ameliorate the problems defined by the movement members. It is when alliances are formed between individuals and groups in the movement, largely in response to more concerted efforts by the host society to increase its processes of repression aimed at the nascent movement (seen in the provocative acts and by inactivity on issues threatening vital interests of movement actors).

The third stage suggested by the model is institutionalization. The movement is now characterized by a large base of members and resources; an extended division of organizational labor; and by its thrusts into political arenas. This entrance to the political realm may also result in the formulation and enactment of legislation designed to "solve the problem" that the movement has defined. At this stage, the movement is at the peak of its power, and the societal response represents the acme of its cooptation efforts.

The fourth stage, fragmentation, is the beginning of the movement's decline and is attributed to the effect of cooptive efforts by the host society which divide the membership. Some people in the outer ring now accept the redefinition of the problem offered by the host society and believe that things have really improved. The inner two rings, deprived of outer ring supporters, give way to in-fighting over future direction and tactics that will achieve desired goals. Disagreements over the goals of the movement are also common during the fragmentation stage, some arguing that the original goal was never attained, others that the goal should now be modified, and others who believe the original goal should be replaced with a new one. These dynamics reflect changing requirements of leadership as well.

The final stage in the model of social problem-movement careers is demise. Mauss cautions that some in the movement may see this stage as success, since most of its stated goals have been achieved through cooptation. It might also be seen as a "temporary set-back" in an otherwise vital movement. In any event, it is the stage characterized by the cooptation of the leadership and most of the members. Those on the fringes of the movement (i.e., those resisting cooptation) are now seen as no longer legitimate, having departed from the direction of the leadership and most members. The mixture of response is now almost total repression from society toward the movement's "fanatical," "hard-core," "true believers;" all others have been coopted away from the movement.

This stage analysis is an "ideal type." Departures in practice are expected, but Mauss defends the model as credible because the life cycle of a social problem-movement occurs independently of objective reality:

> It had its inception in the collective definitions of its members and sympathizers of the nature of reality, and it is moved through its various stages by its interactions with the host society, an interaction which involves a process of mutual definitions and selective perceptions....No objective change is needed in putatively problematic social conditions to make the life cycle run its course (Mauss 1975, 66).

The theoretical wisdom of this latter notion is called into question by the history of the consumer organization and its "champion," Steven Ashton, that follows. To ground the "social problem-movement" Alternatives By Consumers, it should be recalled that historical developments within the mental health movement itself, whose outcomes depended on a social structure flexible enough to undergo change, are the bedrock upon which issues of patients' rights and funding for "consumer-developed alternative services" could emerge at all.

ABC's First Champion: Steven Ashton

Armand Mauss (1975) suggests that "champions" of social problems are people "who, in their own interest, attempt to influence public opinion and the collective definitions of reality, and who thereby generate social problems via social movements" (Mauss 1975, 11). Clearly, Steven Ashton, founder of Alternatives By Consumers, was motivated by his inpatient and outpatient mental health care experiences to form an alternative treatment consumer-run organization. There is little doubt that he does influence people and their way of thinking. People often mention his charisma.

Charismatic Presentation of Self

Trying to capture Ashton's charisma in field notes and analysis has presented a continuing challenge since 1983, when I did my first field work at Alternatives By Consumers (ABC). His influence on a crowd, peers or professionals, is the time when his dynamism is most evident. Two excerpts illustrate this below. The first occasion was a presentation made to inpatients at a community hospital about the organization:

> After introductions, Ashton began to speak....He told them about his own experiences: the accident; ... his voluntary [and] ... involuntary hospitalizations; ... his terror and trouble with applying for [disability] benefits; ... his struggle to find work; ...and his continuing work in therapy. ...Throughout the presentation, he repeatedly used phrases like "we are here for each other; we can do it ourselves; we don't need professionals to do things we can do;" and "we are here to help with your fear..." (Field notes St. Lawrence Hospital October 13, 1983).

Ashton's public presence is powerful is because he draws listeners into a web of identity with him, and not only on the grounds of mental health consumerism. His remarks speak to core issues of the human condition: fear, struggles, the need to relate to one another. His courage to self-disclose in public places about topics thought "taboo" also engages his audience.

The excerpt below shows how little he alters his stance before professionals and community leaders. These notes were taken during a talk he gave to members of the Michigan House of Representatives mental health committee in 1983, just as consumer-run programs were beginning to receive state funding.

> The members ... returned to a position of riveted attention as Ashton began ....'I'm very fortunate to be here....because ... my wife and children did not desert me. When I became ill.... "I wanted to ask someone:...

> Can't you see I want to work?".... `[People tell me] "I'm a mental patient" [or] "I'm sick."'... "I don't blame my father for the abuse I received or getting sick. The parents aren't to blame. It happened: Go on. How are we ever going to get well if we are always seen as sick?"...."I tell [providers] ... I'll show you reality: ... people with no homes; people living on the street; people being arrested for having needs..." (Field Notes, Capitol Building, November 8, 1983).

The topics Ashton spoke about held something for everyone to relate to: those without a history of "mental illness" can still identify with feelings of despair; the supportive love of family or friends during times of trial; the tug of desire to look back and blame people in our past who hurt us; and the poignancy of description that illuminates the plight of people who suffer effects from long-term inpatient care.

Ashton's ability to influence people was something he was aware of as well:

> I found I had a special skill in motivating others to speak or feel good about themselves so that they could advocate on behalf of themselves, and not be ashamed....I found I had the skill of leadership with running a meeting and ... confidence that I could do this without fear of the consequences because I knew this was ... right ... (Ashton 1983).

Thus, Ashton's leadership ability is not solely charisma: it is a skill that evolved as he advocated for and with other consumers.

A Champion with More Than Self-Interest

Mauss' description of champions as people operating "in their own interest" is not without its parallels to Ashton's experiences with ABC. He does have a self-interest in the organization, having gone from full-time volunteer to paid Executive Director of the organization. The issue for him is neither conflict-free nor is it his singular reward:

> I'm employed because of ABC. I feel ... guilty that I have profited by it...[because] it also allowed me to grow in a creative way ... I had the opportunity to ... finally know who Steven is, to be Steven. ...But also, ABC allowed me ... to meet thousands of people ... and each one has given me something, whether it's a professional, or a legislator, a family member, or a patient. ... I guess that's the profit (Ashton 1987).

The reward Ashton realizes, a discovery of self, is what he tries to kindle in others, and what he attempts to teach to his diverse audience.

> I really am dedicated to talking to other individuals who think their life is ruined because of their past. Now I have the opportunity to say to them that you can find a person within you...you don't need to always dwell on whatever happened to you yesterday....My main reward is hearing people talk about who they really are instead of all the bad feelings (Ashton 1983).

Ashton calls forth new definitions of self, and in the process, alters collective reality. Perhaps in his leadership role to people labeled "mentally ill" and advocates he does not generate a social problem, as Mauss would have it, but rather a social solution to the problem long denied: lack of effective and supportive mental health care.

When asked why he formed the organization, he drew on his own experiences but conceptualized his motivation in "other-directed" terms. These were some of his thoughts on why he founded the organization, two years after its inception:

> I guess my own experience with the mental health system, knowing that the closet door was still closed, and ... the abuse after hospitalization. I felt that somebody had to step forward, regardless of the consequences. ... I felt strongly that if I persisted, others would eventually come forth (Ashton 1983).

It was apparent to Ashton that the problems which plagued his reintegration to the community following psychiatric hospitalization during the late 1970s were shared by nearly all returning consumers. This realization became the springboard for his efforts to alter "collective definitions of reality" (Mauss 1975, 11) of the mental health care system as unilaterally beneficial for those subject to its treatment practices.

Treatment Experiences and Social Vulnerability

Ashton's experiences in the mental health system were not unusual. From the selected events in his history which follow, much is revealed about the plight of Everyman/Everywoman in the U.S. mental health care system. We see how effects of the political economy; the stigma of a "mental illness" label; the degrading treatment programs; the use of psychotropic medications; and the loss of disability benefits all contribute to the social vulnerability any consumer might experience. Each factor adds to individual distress.

In many ways, the story of ABC's growth is a story of Ashton's growth and rebirth after his bout with emotional problems. His devotion to the self-advocacy cause has been long-standing and stems from the "awakening" (as he calls it) that he realized following a serious on-the-job injury while working full-time as a machinist. All of his life, he had defined himself in terms of strength and physical prowess, seeking to overcome the usual social discount given men of small stature. The threat to his body resonated internally as a threat to his very identity. He had "lost" the only self he knew.

Physical disability prevented his return to manual labor, and lack of other job skills or educational credentials (beyond a high school degree), closed most avenues of livelihood known to him. In 1978 he was unemployed and scared about his future. The stress and terror of this physical disability period lead to a "nervous breakdown: I knew something was wrong, something had changed in me but I didn't know what it was" (Ashton 1983).

Ashton's entry into the realm of mental health care was not unusual. Many people in the U.S. are referred for mental health treatment by practitioners they consult for other reasons (Rosengren 1980, 98). At the time, Ashton consulted his family physician when he was having problems sleeping and experiencing bouts of crying which he could not attribute to a specific cause.

> [M]y family physician ... didn't know any psychiatrists, so he just pulled a name out of a hat. I went to this psychiatrist and he wrote up a prescription for psychotropics[1] and I didn't know what it was. ...Because I was already crying and broken...I took the medication and I couldn't sleep. My family physician had already prescribed Librium [a minor tranquilizer], so I was taking that and the psychotropic, and I couldn't sleep and I went back to the psychiatrist. He [said] ... I should take some more Librium....I got very angry and ... told him I wasn't gonna take any more of the junk, and I gave them back ....When I went to [another psychiatrist], he put me on Thorazine [a major tranquilizer]...and I just got worse

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[1] "Psychotropics" is a reference to major psychiatric drugs, which usually include major tranquilizers (also called antipsychotics), antidepressants (closely related to major tranquilizers), and lithium (also called an antimanic agent). Minor tranquilizers (e.g., Librium, Valium) are less frequently used in-hospital. Despite common terminology, no drug has been found to be specifically anti-psychotic, anti-depressant, or anti-manic (Breggin 1983, 4).

(Ashton 1987).

Ashton's experience with psychiatric drugs is also prosaic. People are told that the drugs will alleviate the troublesome symptoms (i.e., coping difficulties) that stimulated the search for professional help. Ashton's initial response, anger at having been prescribed them, is common. But expressing that anger openly at a professional is a luxury afforded to few in the public mental health system, where recrimination is standard. It seems reasonable that this was an artifact of his outpatient status at the time.

As Ashton continued his mental health care trajectory, his experiences with medications and the professionals who prescribe them poignantly reveal the treatment and lack of information accorded most public system <u>or</u> private sector mental health consumers. Here Ashton responds to my question about the effects of the medication:

> I became paranoid....My eyes became blurred, I couldn't read the paper...I was afraid to drive because of my perception and reflexes....it was like slow motion. I lost my sexuality....Everything was gone....[The] para noia ... was...embarrassing ...I hear a car sitting outside my house and I think they're gonna come in and kill my kids....or I hear gun shots and there'd be no gunshots. I wasn't schizophrenic, it was the medication.... That never happened before. Or after.
>
> I went to the doctor and said that I can't [keep taking these]. And he ... never told me what was going to happen [until it did]. I got really angry cause ... this medication was doing these things to me....the major tranquilizers just made me more depressed. More helpless, unable to function (Ashton 1987).

Above, we see that fear interacts with Ashton's original anger about medication prescriptions: the layering effect of social vulnerability elicited by treatment experience has begun.

Ashton continued to feel suicidal and depressed. Soon afterward, he made a suicide attempt during his psychiatrist's vacation, taking an overdose of psychotropic medications. When he awoke from this attempt, he was fearful. In his desire to consult someone that day, he went to see the person standing in for his psychiatrist. When Ashton reported feelings of fear and self-loathing, they were tied to a standard psychology text-book finding, and Ashton deferred to professional knowledge about the 'true' meaning of these feelings. He followed the subsequent recommendation for treatment:

> The first [time][1]....I was sort of coerced into signing myself in...because I attempted suicide earlier in the day....[I was] told that if I didn't go to the hospital, I'd probably go home and kill my wife and children [because being suicidal meant I was homicidal].... I was overwhelmed by the suicide attempt, and then the comments ...were even worse. I didn't know how bad I was but, the man said it, so, I signed myself in (Ashton 1987).

In this instance, professional communication provided definition for Ashton's experiences and hospital treatment as appropriate redress. In this social setting, Ashton's vulnerability contributed to his acquiescence.

While an inpatient, Ashton was kept on psychotropic medications. When he was discharged a few weeks later, he continued to feel depressed and suicidal. During his interview, he identified a hospital dynamic affecting many consumers:

> [I]n my first hospitalization, I attempted suicide [and] I

1.Ashton was admitted to a private hospital ward because he was covered by his wife's insurance policy, a benefit of her job.

> left suicidal....It never went away....I was afraid to even talk to [hospital staff]....If I told them I still felt suicidal, they'd lock me up for just sharing my emotions. So I wouldn't do that (Ashton 1987).

Through the events surrounding his first hospitalization, Ashton learned that honest disclosure to professionals in the care system might instigate or prolong his hospital experience.

When Ashton returned to his home, he received notice that a review hearing had been scheduled to determine whether he still qualified for disability benefits. At the hearing he learned two things:

> I didn't know I was mentally ill....until I went to a Social Security hearing and they had labeled me as borderline-schizophrenic....I was drawing Social Security disability [SSD] in 1979. It lasted for one year and then I was cut off....[even though] I was still under the treatment of a psychiatrist (Ashton 1987).

Welfare bureaucrats taught Ashton how grave his condition was, paradoxically rendering judgment that the condition was not grave enough to warrant economic support during rehabilitation.

Again, Ashton's experience mirrors that of thousands of other mental health consumers during the early Reagan years. Other administrations had attempted to curtail services available through Community Mental Health Centers (CMHCs)[1], but Reagan's administration went a step further with a two pronged attack on the CMHCs <u>and</u> the individual:

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[1] "In 1973, Nixon illegally impounded CMHC funds already appropriated by Congress. The administration claimed that the CMHCs were ineffective....[I]n 1975, Ford sought to impound funds which were running the CMHCs on an emergency monthly Congressional appropriation...." (Brown 1985, 54-5).

> A crisis turned to scandal. Budget cuts, Medicaid caps and National Institute of Mental Health reductions weakened the already troubled CMHC network. The purge of SSI disability rolls that began in 1981 singled out the mentally disabled. More than half of the estimated 47,000 people whose benefits were terminated suffered from mental illness (Walsh 1984, 3).

Loss of disability benefits contributed to Ashton's suicidal depression. An additional layer of social vulnerability, economic insecurity, increased his coping dilemmas.

As the depression continued unabated, Ashton voluntarily sought hospitalization. This time he drew upon his Veterans Administration (VA) benefits (he had been in the navy) and admitted himself to a psychiatric unit at the VA Hospital in Ann Arbor, Michigan.

> The staff was mostly ... young, aggressive people, anxious to cure and help....They did a lot of good even though they were inexperienced, even in group therapy. They ... were good...(Ashton 1987).

It is noteworthy that young and inexperienced hospital staff communicate the expectation that psychiatric conditions can be cured. In their care, Ashton characterized this quality as helpful.

At the VA hospital, the staff took Ashton off the major tranquilizer when he did not "fit" the diagnosis that would justify its administration.[1] Although the manner in which they switched him to new medications is usually avoided, it is

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[1] Administration of specific psychotropic medications according to a given diagnosis continues to be a standard in mental health treatment, despite amassed research that indicates the fallacy of this alleged scientific notion (Breggin 1983; Hill 1983).

still practiced.[1]

> A battery of tests ...said I wasn't schizophrenic, so [they] put me on an anti-depressant[2] 'cause I was suffering from depression. I had withdrawal cause they took me off Thorazine cold turkey. For a week I was sick. I couldn't sleep. I'd vomit, I couldn't sit up in a car....Then they had me on anti-depressants, which was like a miracle...I was so heavily sedated, and then all of a sudden, this whole new world came. You ...could think and you could feel and you could see and you could laugh.... Taking me off the major tranquilizer, ... probably was just as effective as putting me on an anti-depressant. I probably didn't need the anti-depressant, but it [brought] balance back (Ashton 1987).

Ashton was unable to distinguish his own coping problems from those evoked by the major tranquilizers until treatment with them ended at the private hospital. Most consumers in the public system with diagnoses of schizophrenia (or others labeled psychotic) rarely have this opportunity once treatment with major tranquilizers begins.

When Ashton returned to the community from the VA hospital, he was unemployed and without disability benefits."I had to go to [the] Community Mental Health [Center]. That's when I began dealing with the public mental health system" (Ashton 1987). He went to Community Support Services (CSS), seeking a therapist for individual therapy. (CSS is an adjunct agency for many Community Mental Health Center agencies which offers outpatient care.)

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[1] Shortly after I interviewed one young man from ABC for this project who wanted to eliminate his dependence on psychiatric medications, ABC staff learned he had been admitted to the local psychiatric ward in a community hospital through its emergency room. Under his doctor's supervision, he was taken off his medications "cold turkey," resulting in near-fatal renal failure.

[2] Breggin notes these are closely related, in chemical structure and clinical effects, to major tranquilizers (1983, 4).

Ashton was referred to a CSS psychologist who would prove to be an enduring source of support.[1] One of her first suggestions was for Ashton to attend the "day treatment" program (also called a "partial hospitalization" or "partial day" program) offered to a combined population of inpatients and outpatients.

> ... At day treatment, [I] had the three basic things: group therapy, crafts, and recreation...But [the only thing] ... beneficial about it was that it took me away from my home,....away from my security. I got out of the house. ... And there was people there I was in the hospital with [and that was a benefit] ...But as to the group therapy and the crafts, ugh! (Ashton 1987).

Still vulnerable in social settings, Ashton appreciated the chance to break his isolation <u>and</u> be with consumer peers.

Ashton's inculcation into the public system drew him into an orbit of providers who work with public consumers. When he had exhausted the day treatment benefit[2], he was referred to Vocational Rehabilitation Services.

> Vocational Rehabilitation Services [VRS] began a program called Charter House ...designed after Fountain House in New York.[3] It was gonna be a consumer run drop-in from 10-2, and they were gonna have a little lunch. ...[After day treatment ended, VRS] sent me over there....It was devastating....I would only work about 15 minutes, doing

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1.Ashton had been in psychotherapy for nine years with the same person at the time of our interview (November, 1987).

2.Under Medicaid guidelines, public mental health consumers can be subsidized for up to 3 months in a day treatment program. When this time limit is reached, benefits end. In demonstrably exceptional cases, the benefit may be extended for 2-3 weeks.

3.Fountain House began as a self-help group, We Are Not Alone (WANA), formed by Rockland state hospital expatients in the 1940s. After professionals became involved, its name and mode of operation changed drastically. For discussion of its demise as a consumer-run program, see Chamberlin (1978, 87-90).

> maintenance, fix a drawer,...and the rest of the time I'd sit there, [smoke cigarettes] and watch people pace.... People would prepare lunch [then]...serve it as waiters and waitresses. It became depressing....Sometimes, I'd go out on work crews. I [had] a sitter with my children [for] ... $2 an hour; I'd work for an hour and get $3. It was crazy. Washing windows, [mowing the lawn] ...just for an hour....I didn't mind working or ...being productive ... [but it wasn't real work] (Ashton 1987).

Unemployed consumers enter vocational rehabilitation programs to learn and/or redevelop useful job skills, hoping to earn money as well. Ashton's depressing experience with the Charter House program is shared by other ABC consumers. Some characterize such programs as "false promises" (Interviews # 3, 4, 10, 13).

Vocational Rehabilitation Services (VRS) counselors continued to seek placement for Ashton. His path to eventual employment was circuitous, and reveals the lack of follow-through planning that is endemic to many rehabilitation programs:

> Eventually [VRS] said there was a job for me at some bakery ... where they place "these people," ... and I'm one of "these people." The day they were gonna take me over there, something happened. They closed down or something. I was all ready to try to go to work.... I was accepting that (Ashton interview, 1987).

Disappointment and frustration accumulate over time for persons attending vocational rehabilitation programs. Ashton's experiences with such programs is far more limited than most. Many ABC consumers have been assigned to the Charter House program 7-8 times, and most have similar tales of dashed hopes for promised placements.

When the prospective job evaporated, Ashton's Vocational Rehabilitation Services counselor suggested he return to school and build new job skills for a different future. Still on medications for treatment of depression, Ashton enrolled in a community college. Although he was now taking anti-depressants instead of anti-psychotics, over time the effect of both drugs proved to be the same:[1]

> The medication...made me suicidal and depressed. ... I even drooled without knowing it... It scrambled my mind and made it impossible to study or concentrate at all (Ashton 1983).

Accumulating layers of social vulnerability, exacerbated by treatment in the system, took their toll. Depressed, suicidal, economically insecure, unable to study for school, involved in "emotionally exhausting" therapy, and connected to a vocational rehabilitation program that offered neither vocation nor rehabilitation, Ashton made his most serious suicide attempt.

> The third time I attempted suicide I was in a medical heart unit at [a local hospital]....I almost died ...because of the severe [damage] to my heart and liver ...that had taken place...because I had overdosed [with] psychotropics ... (Ashton 1987).

Ashton again reflects a common experience among consumers prescribed self-administered psychiatric drugs. Ineffective for help with coping difficulties, the drugs can be used as a weapon against the self. In my small sample of ABC consumers, only 3 of 15 people did <u>not</u> use psychiatric drugs in a suicide attempt.

Ashton's admission to a medical, rather than psychiatric, unit was a turning point. The juxtaposition of these different

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[1] The similarity in effect is no coincidence (see Breggin 1983).

hospital experiences illuminated the stigma of "mental illness" that had a profound impact on his own mental patient trajectory and his subsequent advocacy efforts with, and for, others.

> I was still depressed, but I felt a thousand times better than I did the two previous discharges because I was ... not on a psych. unit. I had respect for the nurses and the doctors and the patients ... there.... They ... treated me like a human being. One nurse wanted to know if her minister could come and see me ... I thought that was really nice, that they were concerned. They accommodated my needs [and] didn't try to force anything upon me....It's had a lasting effect ... it was a different understanding (Ashton 1987).

Ashton's exposure to humane hospital care and surcease of psychiatric medications marked the end of his inpatient career. Either of these constitute rare events for most public mental health consumers.

Beginning Again, Amidst Consumer Peers

After discharge, Ashton returned to the vocational rehabilitation counselor. He learned of new possibility for employment, through a CETA (Community Employment and Training Act) position[1] at a human service organization in town, the Center of Handicapper Affairs[2].

Ashton's placement at the center was fortuitous. The

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[1] CETA was one of the few programs that allowed federal subsidy for human service employers hiring handicappers with physical or mental characteristics of note. It ended in the first year of the Reagan-Bush administration (1981).

[2] The Center of Handicapper Affairs is an Independent Living Center in the Lansing area, accredited by Michigan Rehabilitation Services.

CETA program allowed Ashton's reentry to competitive employment, despite his psychiatric label. Regrettably, this program was disbanded in 1981. There have been few programs offering similar opportunity to public consumers involved in Vocational Rehabilitation Services since that time.

Ashton held the CETA position from September, 1979 through March, 1981. In his position as a coordinator of transportation for physical handicappers, he was exposed to civil rights efforts being pursued by advocates for the developmentally disabled and mentally retarded adults and children. One special population did not yet have a voice.

> When I began to work at the Center of Handicapper Affairs, I [learned] about [Michigan House Bill] 504 [for handicapper rights] and civil rights and I found that there wasn't any involvement by the consumers in the handicapper [advocacy] movement dealing with mental illness (Ashton 1983).

In the supportive atmosphere of the Center, Ashton's extreme social vulnerability waned. The Center director saw Ashton as capable, and Ashton was earning money while pursuing meaningful work. He soon met other mental health consumers interested in addressing grievances with the care system.

> I met a young lady who was studying to be a lawyer who had been in the mental health system as a client, about twenty years earlier. She wanted to--we wanted to--organize a group to advocate at the State Capitol and she went and wrote an article in [the Center of Handicapper Affairs newsletter], asking individuals who are expatients to come forward at the Capitol and testify (Ashton 1983).

These events typify important features of deinstitutionalization in the sociocultural context of the times. Interest in civil rights for minorities in the 1960s fueled interest in civil rights for handicappers with either physical or mental characteristics. At the same time, deinstitutionalization practices funneled expatients back to home communities following their incarceration in state hospitals. Consumers with patients' rights interest drawn to existing advocacy organizations in home communities were soon exposed to others' stories of ineffective and/or degrading mental health care. This raised consciousness about the social aspects of experiences largely considered personal before.

Ashton's response to the organizing idea raised by the law student reveals the knowledge he gained from his experiences, his deep empathy with the situation of others, his belief in a strategy specific to the population of consumers, and his "philosophical difference" which would later manifest itself in his idea of advocacy through "gentle justice."

> I told [the law student] that ... because of the stigma, people will not ... stand up and say "I'm mentally ill" or "I'm a schizophrenic" ... because ...they would lose their jobs or feel guilty or ashamed ...So I met with 5 other people in the state who were ... medical advocates [and expatients], and we tried to organize but ....We were so philosophically different in our approach that it just wasn't workable (Ashton 1983).

When Ashton discovered mental health consumers who could embrace his philosophy, the metamorphosis began: he would soon don the mantle of leadership in ABC's "gentle justice" advocacy efforts. The "social problem-movement" for consumer-run alternative service programs was underway.

Alternatives By Consumers as a Social Problem-Movement

The evolution of the consumer organization ABC, detailed in the following chapter, demonstrates interesting parallels to and departures from the theoretical model of "social problems as social movements" (social problem-movements) developed by Armand Mauss (1975). Alternatives By Consumers' organizational history displays specific stages of growth that parallel the "ideal type" stage analysis Mauss proposes in some aspects (i.e., periods of "incipiency," "coalescence," and "institutionalization"). However, any structural model is characteristically enabling _and_ constraining. The Mauss model enables sense to be made of ABC's chronology of events, but it constrains "bracketing the natural attitude." The latter thwarts an understanding of events as actors _intend_ they should be understood. The model imputes social actors' intentions and allows no methodological way of correcting for these assumptions. It also incorporates mainstream biases of the society (e.g., sexism, racism, professionalism, classism). (These themes are elaborated at the conclusion of Chapter 5.)

Mauss situates study of social problem-movements within the larger cultural context, incorporating the idea of historical relativity in the model. Specific social movements arise following periods of general social change (i.e., "cultural drift"). These specific social movements are dedicated to restoring, protecting, modifying, or creating norms or values in the name of a generalized belief (Mauss 1975, 45-46). Thus, social problem-movements can be characterized as either norm-oriented or value-oriented. Most reform or revisionist movements in the U.S. are norm-oriented, since value-oriented movements strive to change the culture as opposed to seeking change within existing social structures. Within this terminology, the ABC organization is a "norm-oriented" social problem-movement seeking change within the existing framework of the mental heath system. Its provision of "alternative services" through a consumer-run organization challenges the routine of traditional practices within the system, but does not challenge the basis of U.S. culture itself.

However, an alternate vision of the organization is possible. When the intention of the social actors involved are revealed, the analytical distinction between a norm-oriented or value-oriented movement is blurred. While ABC is involved with providing alternative mental health service opportunities to consumers, its founder is vociferous in advancing the ideas of "gentle justice" within the society and helping consumers become empowered. If working-class expatients deny power to those who would stigmatize them, forge service organizations that threaten to undermine the profit-motive and the professionalism, sexism, classism and racism that characterize traditional mental health care, then the basis of the culture _is_ challenged and its overall framework threatened.

"Gentle justice" becomes the generalized belief that challenges the culture of a society "...pervaded by an ethic of dominant/subordinate power relations" and based on "interacting structures of domination" that include race, sex, educational achievement and professional standing (Wineman 1984, 33). Due to interaction between structures of domination, a challenge to professionalism, the most apparent feature of ABC work, challenges the overall framework of U.S.

society.

Thus, by theoretical manipulations of the Mauss model, it can be argued that ABC is <u>both</u> a norm-oriented and value-oriented social problem-movement which arose following a period of widespread social change in the 1960s and 1970s. The "cultural drift" toward civil rights concerns birthed new activities in the patients' rights arena, and the consumer organization, ABC, provides an "exemplar" within this "class of possibles." And yet, practices of ABC consumers in their role as peer-advocates demonstrate tension in the broad organizational stance of "gentle justice." Sometimes justice is achieved by helping an individual attain desired treatment (e.g., psychiatric drugs) and other times it is achieved by helping an individual refuse a practitioner-desired treatment (e.g., psychiatric drugs).

The issue of norm-oriented and/or value-oriented movement can only be assessed by examining data which allow the intentions of the social actors involved, ABC consumers, to emerge. This is the task of the next chapter, as a stage model theorized as endemic to the growth of social problems and social movements is illustrated and contrasted with data from this project. The theoretical base suggested by this model will provide the first appraisal of ABC as a social problem-movement as its development is detailed. Following the stage analysis, a second level appraisal will then be made of apparent deficiencies in the model, and other theoretical vantage points will be considered that provide greater illumination into the meaning of the organization's activities.

CHAPTER END NOTES

(a)The use of quotation marks in the phrase deinstitutionalization "policy" is deliberate. It alerts readers to the controversy over conceptualizing it in this way. Phil Brown, for example, devotes a full chapter in his book (1985, 26-43) to analyzing the question of whether deinstitutionalization--or any other national plan in U.S. mental health care--can appropriately be described as "policy."

(b)"There is a strong case to be made that deinstitutionalization was never really attempted. The network of local, decentralized health services it took for granted was never established, and its most basic precondition, affordable housing, disappeared" (Walsh 1984, 3).

(c)"In short, a specific social movement is a kind of social organization, though not always organized as established groups and institutions. Its organization and other characteristics are not...present from the beginning, but they develop with the passage of time, largely out of interaction of the movement with the rest of society" (Mauss 1975, 45).

CHAPTER 5

CASE STUDY, PART II: NATURAL HISTORY OF ALTERNATIVES BY CONSUMERS, A STAGE ANALYSIS

Introduction

In the previous chapter, possibilities of applying the Mauss (1975) concept of social movements as social problems to the formation of the Alternatives By Consumers (ABC) organization were briefly considered. The application reveals certain departures from tenets of the model. First, the notion of "champion" for a social problem-movement does not embody the unique situation of a mental health consumer in such a leadership role. Secondly, Mauss' contention that social problem-movements are predominantly norm- or value-oriented does not accurately portray the unique situation of a mental health consumer-run advocacy organization whose work embraces both orientations. Thirdly, tension between theoretical tenets and practical applications is particularly acute with respect to the idea that discrete temporal boundaries exist for any social problem-movement's development over time. Exploring the events that coalesced in Steven Ashton's emergence as a leader and champion for the problem-movement (in Chapter 4) indicate that the predicted chronology of development did not apply to his efforts. In this chapter, I consider whether the stage development Mauss outlines applies to the natural history of ABC depicted in the ensuing discussion.

Mauss argues that champions of social movements emerge as social problems are generated by collective efforts. For ABC, however, the leadership of Ashton had to be in place before the ad hoc organizing efforts, characteristic of the incipiency stage, could occur. In part, this has to do with the nature of this population. Ashton correctly points out that the stigma of the label would prevent most people from declaring their psychiatric history in public. The growth of the organization over time, examined in this chapter, reveals that a leader willing to bear the brunt of public scrutiny had to emerge before the group could organize.

Moreover, Ashton's ability to handle public scrutiny, in lieu of other ABC participants, allowed the organization to continue--and extend--its advocacy efforts through its first three stages of growth, "incipiency;" "coalescence;" and "institutionalization." I provide details of these three stages for the Alternatives By Consumers organization, noting parallels to and departures from the Mauss model within the discussion.

The case study concludes by offering a critique of the social problem-movement model. Inadequacies of this theoretical model reveal the need to attend to objective conditions and social processes that Mauss' conceptualization, representative of most social problem and/or social movement literature, eschews. The conflict perspective critique illuminates some of the problems inherent in applying a structural-functionalist model to conditions and processes marked by dynamic contestation. In the discussion, attention is focused on the interface between the organization and the traditional mental health care system; the manifest and latent consequences of ABC advocacy efforts for the organization and its participants; and effects of these efforts on practices which reproduce or alter workings of the larger care system.

Stage One: Incipiency, 1979-1981

As debates over philosophical differences among the expatients gathered at the Center of Handicapper Affairs where Ashton was employed continued, an important feature in the group's incipiency was selection of a name:

> When we tried to come up with a name, I came up with ... [Alternatives By Consumers. We wanted to be the ABC's of mental health and gentle justice; to stand for alternatives to the unjust conditions we knew.] I felt ... advocating for justice in the mental health system was not all that we were looking for, it was justice in our lives [and new alternatives]...[ABC, working for gentle justice] sounded strong. That's how it began (Ashton 1983).

Naming the group constitutes beginning efforts to define the problem that advocacy efforts will address. Other "firsts" for the organization were less focused, as Ashton and other early core supporters struggled to mark their own territory for subsequent advocacy efforts.

The First Protest Demonstration

Plans were made to demonstrate at the offices of the Michigan Department of Mental Health in downtown Lansing. It was a provocative event for the groups' passage from an informal to a formal organization. It also evoked a response that would provide a significant link in the bridge Ashton was building between mental health consumers and professionals.

> We felt strongly about [two issues]. One was employment, hiring individuals who were suffering from emotional and mental problems, and ... overdrugging. Or drugs, medication themselves. ... So we marched downtown on a Sunday ... and that's kind of ridiculous ... with our signs and no traffic and the TV people came down...and we were talking [to them] about the overdrugging in the institutions (Ashton 1987).

The demonstration garnered some media attention, including TV coverage, but few consumers attended. It did, however, bring a response from officials in the mental health system. According to the Mauss scenario for the stage progression, the response was the first cooptative effort.

After the demonstration, Ashton and other demonstrators were invited to meet with Dr. Frank Ochberg, then Director of the Michigan Department of Mental Health (DMH). Shortly afterward, Ochberg asked Ashton to participate in an informal sensitizing pilot program with him and other mental health professionals from various state institutions (e.g., psychiatric hospitals at Northville, Clinton Valley, and Yorkwood), interested in improving doctor-patient relationships. Two or three months after this initial meeting, the "Professionals and Consumers United" group began to meet on a regular basis once a month. The group held together for about 2 years, meeting at professionals' homes and offices across the state. Interest in the group from all parties waned over time, and eventually the group died out.[a]

Another formative development stemming from this demonstration, and the in-group controversy about it, was the exit of an early ABC expatient/advocate from the nascent group.

> I did have ... problems from the individual that I met and originally talked to starting ABC about ... she was so radical in ABC that people wanted to leave. They didn't agree with her. She would say that if we didn't agree with her that we were <u>for</u> commitment or <u>for</u> drugging or whatever...Fortunately, she went down to Detroit to finish up her law school. After that...we really .... blossomed (Ashton 1987).

The lack of fit to the Mauss stage model is illuminated by this incident, which Mauss typifies as "normal fragmentation," occurring after a movement has enjoyed a period of success. The three characteristics he identifies for the fourth "fragmentation" stage apply to these early events: "...redefinition of the situation will cause [supporters]...to drop out";...."[supporters] will fall to fighting among themselves about...tactics for the future";...and "different styles ...of leadership [are]...at stake" (Mauss 1975, 64-5). Moreover, movement participants will "join with ...society in labeling the uncompromising purists in the center circle as 'fanatics'...." (Mauss, 1975 64). Contrary to Mauss' suppositions, the event depicted contributed to the <u>solidarity</u> among ABC supporters, not fragmentation. Mental health consumers demonstrate an early need for definition and consensus about collective activities to pursue. The social problem-movement model does not accommodate these special needs.

Incorporation of ABC

Soon after the "radical" organizer left, Ashton and his informally organized group moved to incorporate as a non-profit charitable business corporation, comprised of non-stock-holding members. When Ashton lost his CETA position at the Center of Handicapper Affairs in March of 1981, the incorporation papers had just been filed. Ashton was named as the full-time (volunteer) Director of ABC.

By consensus, the group decided ABC membership should be open to any former or current consumer of mental health services. There are no formalized rituals of membership: no membership roster is kept, no membership cards are issued. When asked for a definition of an ABC 'member' Ashton states: "Anyone who identifies with ABC is a member" (Field notes, ABC office 1983).

ABC members at the time of inception nominated and elected a 4 person consumer Board of Directors then drew up By-Laws, intentionally keeping them as unstructured as possible. Board members were to serve in an advisory capacity to Ashton as Director. In practice, this seldom happens. ABC Board members knew Ashton as their leader, not their follower. Board members were diligent in meeting with Ashton regularly, but were reluctant to abandon their early role prescription for him. (This ascription has been immutable to change, despite variations in Board composition.)

The Outer Ring of Support Takes Form

Ashton's early forays into the community were significant for the group's continuation. Ashton was not sure he could pay office rent without his CETA funds. When MAEDC, the Michigan Association for Emotionally Disturbed Children[1], learned of his financial plight after he made a presentation before their group, their membership voted to support Ashton and the ABC effort by paying rent and telephone costs for one year. Ashton refused to take money for salary from their contribution.

By serendipity, Ashton had earlier been encouraged by his therapist to pursue a claim against the Social Security Administration, seeking disability benefits they denied him at his first annual review. The call for the second hearing came just as Ashton was facing the ABC funding dilemma. His claim was upheld and he received past benefits in a lump sum. With this money he pursued ABC organizing activities, supplementing the MAEDC contribution for on-going office and individual advocacy expenses (e.g., coffee and/or meals for people he met, transportation and parking costs, etc.) not covered by their $250/month donation.

At this time, there was also some evidence of an "outer ring" of supporters rallying to the ABC call for "gentle justice" advocacy efforts. The advocacy Ashton envisioned was for the population <u>and</u> individuals within it. His presentations to

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[1] MAEDC is a parent advocacy group whose children receive care in the mental health system.

state Representatives and hospital inpatients operationalized (reviewed above) this vision. What becomes "consensually defined" as a social problem in these educational, interactive presentations is the literal ignorance of (i.e., the act of ignoring) the plight of expatients returning to community living situations. Ashton did not generate this social problem; he named it and offered social solution to it.

Presentations to community groups were a key factor in the formation of the supportive outer ring, although its strength was established _after_ many advocacy activities had been undertaken. Here again are manifest tensions in the application of Mauss' stage model to ABC development: the actual dimensions of growth defy division into bounded segments of time; and support was rallied for the ABC movement itself. Supporters played no part in naming--or generating--the issues ABC addressed.

In the "incipiency stage" of ABC evolution, the outer ring of supporters included other advocacy groups, with a mixture of professional and lay members; professionals and administrators from Department of Mental Health and state hospitals; members of the Michigan House of Representatives; and a few local hospital staff persons who respected Ashton's individual advocacy with inpatients they knew.

Thus, with ABC's incorporation and establishment of Ashton as the full-time Director, the group passed into the second "social problem-movement" stage, "coalescence."

Stage Two: Coalescence, 1981-1983

Although ABC was now a formal organization, doubts persisted about the groups' future:

> It's difficult to identify what kept ABC going.... There was many occasions where 2 or 3 people would come to our support meeting [and] ...say: this is not going to work, ABC's going the down the drain. And I would say to them: as long as I am here, then ABC is alive....I didn't want ABC to die (Ashton 1987).

Support meetings have been an important feature of ABC work throughout its existence. A description of the group on an early membership flyer suggests the support meeting's significance:

> We are a mutual support group of people experiencing mental or emotional problems. Our membership includes over 100 members in the Greater Lansing area. There is a meeting each week. The content is determined by the members. It gives a chance to:
> -share problems and experiences in an atmosphere of acceptance.
> -to get ideas and learn skills needed to solve problems.
> -to feel needed and grow in self-worth, dignity and respect.
> -to share letters from members who are institutionalized or otherwise isolated.
> -to increase knowledge about the community by learning from one another.[b]

The support meetings allowed a forum for members and a time for planning strategies that advanced their interests in advocacy. As Ashton responded to the needs presented, his knowledge grew.

> When...ABC first began, I had no knowledge of anything other than what I experienced ... but ... being in a courtroom or just being with [ABC consumers having different experiences] let me learn [about] ... going to court on criminal charges, or being evicted, or [being committed] ... (Ashton 1987).

The group expanded its membership base as word-of-mouth broadcasted ABC's existence along the "consumer grapevine" in the system. One early "watering hole" provided links to consumers who didn't visit Ashton's first office. "My first contact [with ABC] was meeting Steven Ashton at [a restaurant],...the quote-unquote mentally ill coffee clubhouse" (Jeff Bell interview 1987). Others heard about ABC while they were inpatients, through friends they made in the hospital. Others learned of ABC indirectly, through contact with the orbit of providers that ABC and consumers share. They return after initial ABC contact, despite felt lack of support on their first visit. And they keep coming back, even when it is an emotional trial to get there.

> I was at a picnic [for CMHC-related programs] that ABC was at. ... But I didn't really ... associate with ABC until ... my roommate ... dragged me in ... to a ... support meeting. I got here early and I was talking to Steven about ... [a pending claim about my coerced admission to a state hospital]. ... He said there was nothing he could think of to help me ... he was really short with [me]. ... [But] my roommate was persistent and I got to know him and ABC people better. ... Sometimes, it would kill to just ride the bus here ... I'd get off ... because I just couldn't stand it ... But once I was [at ABC], I'd feel better. ... People weren't turning away because I was having problems. They were giving to me when I was having problems ... being there for me (Alice Wetherby interview 1987).

Support meetings are more than a drawing card for consumers, although the connection to ABC they allow is often a crucial link to later involvement. For many ABC participants, they present a chance to discover inner strengths in self and others. In a larger sense, the meetings were key for the formation of a genuine community.

> I [went] to the support meetings because ...they were really interesting ... it seemed different ... being around people who could relate, maybe accept you for what you were. I was a shy person, but everybody was so warm and so friendly....[and] I learned things I never learned

> in the hospital ...about mental illness.... I had a different outlook on life [in 1981] ... I was at the point of giving up...but when I began to get connected with ABC ... and began to learn about resources out there that could be of assistance,... I was helping people [and] that helped me (Karen York interview 1987).

ABC Advocacy: Precipitating Events

As ABC participants discovered helping was a two-way street at support meetings, Ashton tried to cultivate a more active membership. He solicited volunteers to help in advocacy efforts and extend ABC's reach to community associations and out-community institutions. Representation on mental health advisory councils and visibility at state institutions were important to ABC's evolution (Ashton 1987). Nonetheless, precipitating events, which Mauss (1975, 56-7) cites as predictable _and_ essential for the development of the second stage in a social problem-movement,[c] did enhance the ABC trend toward coalescence apparent during this period.

One event was when ABC visitors were asked to leave state hospital grounds; another occurred at a public radio station. Both events exemplify the kind of repressive efforts by a movement's host society identified by Mauss (1975, 60) i.e., "...social control techniques ranging from police action to ridicule...." The incident at the state institution involved armed security guards; the incident at the radio station involved social ridicule.

The episode at the Ypsilanti Regional Psychiatric (state) Hospital propelled ABC membership toward "establishing boundaries of group identity" (Mauss 1975, 62) and legitimating activities through development of an "appealing ideology" (i.e., "gentle justice") (Mauss 1975, 56). These are traits of the coalescence period in the stage model.

In March 1982, Ashton and three ABC members visited a woman in the Ypsilanti state hospital, as they had each week for the preceding eighteen months. "Jane" had also been a guest in Ashton's house during holiday passes from the facility. When they went to Jane's ward, they were denied permission to see her. When Ashton returned to ABC after the trip, he wrote down what happened. The following description draws material from that document.

> We went up to [the ward] B-3-3. ...The staff ...said "You cannot visit [Jane]....After your visit last week, [Jane] became agitated. [Her doctor] said you couldn't see her anymore ... only family members can visit her" (Ashton, "Ypsilanti Incident" 1982, 1).

Ashton knew that Jane wanted to see them, so they attempted to speak with the on-site agency mandated to assist hospitalized patients secure basic civil rights, the ORR (Office of Recipient Rights). They were eventually told the office was closed for the day. After speaking with six different people, they reached an office where a secretary listened to the problem, then called her boss in to speak with them.

> I asked the gentleman if it was possible to receive an information release form[1] and have [Jane] sign it so I could talk to her doctor...He said he would make a couple of calls ... After 10 minutes, he ... told me that we could talk with [the doctor if we returned to the ward]...(Ashton, "Ypsilanti Incident" 1982, 2).

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[1] That is, a "Release of Confidential Information" form needed to permit exchange of details about a client. When the client signs it, the information can be released. Ashton's request reveals sophisticated savvy about navigating red tape in the system.

The group returned to the ward, where staff told them to wait for Jane's doctor in the visitor lounge. They were surprised and confused when four security guards appeared and asked them to leave:

> One guard said ... "you intended to take [Jane] out of there any way possible." I said "That's crazy. We came over here to talk to [her doctor] about our relationship with the hospital and [Jane]. He said "I have to do what I have to do."...He informed us that we would be escorted off the grounds and that NO member of [ABC] could visit [Jane] or set foot on the grounds ..., if we did we would be arrested...(Ashton, "Ypsilanti Incident" 1982, 2).

When Ashton reflected on the experience, he felt Jane was now bereft of support in the institution, which saddened him, and was irate at staff treatment of the visiting group:

> What they have done...is everything we have advocated against. We were persecuted ... mentally abused ... false-ly accused ... treated like criminals because we care and love her....They call us crazy, but they are sick! SICK! (Ashton, "Ypsilanti Incident" 1982, 4).

The event solidified the group. Ashton and a few ABC members later return to the Ypsilanti hospital to speak with the Director.

> When we went back, the Director said: "We...didn't mean for this to happen ... We mean to cooperate. We're sorry." But I ... wanted him to know what it felt like to be escorted out of there, let him know why we were there. Then ....they began to appreciate us, wanted us [on] the discharge planning team and wanted us to go [with Jane to visit a group home]...If we hadn't gone back, this wouldn't have happened....[It taught us] you <u>can</u> go back and ...face the people you think are enemies...[and] that the patients there could not speak for themselves.[d] ...[Those] in charge of these facilities are really intimidated and frightened by our presence now....Our questioning has brought about an investigation by the Justice Department... (Ashton 1983).

The power of gentle justice is realized by Ashton and ABC members: the non-aggresive confrontation with hospital administrators allowed voice for consumers and greater latitude for ABC advocacy efforts in the hospital. Ashton also told his contacts at the Department of Mental Health and other patients' rights advocacy groups (i.e., the social problem-movement supporters in the second and outer rings) about the incident. These efforts result in inclusion of the hospital in a nation-wide Justice Department/Senate investigation of state mental institutions. Completed by 1985, the report noted:

> The findings of this investigation demand change. Abuse and neglect of society's most vulnerable citizens must stop. Care and treatment must be provided in an atmosphere of dignity and respect. And those to whom this care is entrusted must be held fully accountable (U.S. Department of Justice Report 1985, 6).

The response from the hospital Director and the onset of the Justice Department investigation following Ashton's contacts with known allies reveal substantial over-lap in the theorized stage progression suggested by Mauss (1975). The formal organization of ABC is theorized as occurring during the second stage, or coalescence period. And yet, the "ad hoc meetings" among people sharing focal concerns, "letter writing" to congresspeople and newspaper editorial staff to "define the problem" (1975, 61-2), which were part of ABC's response to the hospital event, are depicted as events in an incipiency (first) stage. The "thrusts into the political processes of the society" (1975, 63) including the societal reaction, "taking account of the movement with a repertory of routines..." (1975, 64) well describe ABC efforts after the "Ypsilanti incident" and the Justice Department response (i.e., routine investigation of the claims). These are held to be traits of the third or institutionalization stage in the model, when "the movement is at the peak of its power" (1975, 64). Discrete stages posited in the model neither reflect the actual progression of organizational growth, nor allow identification of unique circumstances or needs for the actors involved.

In practice, early ABC advocacy efforts (e.g., in-hospital and House of Representatives presentations; one-to-one activities with patients; informal meetings with other mental health advocates and professionals in the system) provided definition of appropriate strategies and tactics for advocacy imbued with "gentle justice." While specific knowledge about the operations of the mental health system became increasingly sophisticated, the <u>kind</u> of activities pursued by ABC members remain constant over time. This finding departs from the postulated model.

The second formative incident for ABC occurred when Ashton, other ABC members, and mental health professionals were offered air time in a talk-show format. Their panel presentation was slated to follow a video showing of "Back Wards to Back Streets," on a public television station. Its theme was the negative effects of deinstitutionalization for discharged patients who do not find asylum in community mental health service centers, and eke out existence on the back streets of U.S. cities. During his 1983 interview with me, Ashton reflected on the experience.

> I arrived ...with 20 ...expatients who did not care if anybody knew they had emotional problems or been in the hospital...[Studio staff] were going to tape their re-

> sponse to the film, and there would be a call-in to 5 people for the panel .... Then we were told it wasn't gonna happen ... It was like kicking us in the teeth... But we didn't scream and yell, we just accepted something we didn't have control of.... I [was] ... the only consumer [on the panel] with 4 professionals. Unfortunately, ... they [only] chose calls [for] mental health professionals...(Ashton 1983).

Mauss notes that a mobilization repertory includes developing successful strategies to influence collective definitions of a social problem. "Sometimes a successful tactic can consist of no more than a skilled reaction to an unplanned precipitating incident" (Mauss 1975, 56). Ashton's response to the studio incident falls in this category:

> It made me so angry that I ...got 5 people from ABC to tape 2 shows on [the cable community access] channel .... If the bureaucratic system won't allow us to speak, we'll go find opportunity [elsewhere] .... (Ashton 1983).

Ashton's "skilled reaction" went beyond this communication tactic; he also used the incident to teach members gentle justice ideology:

> I didn't allow individuals from ABC to become so agitated that they would picket....I [said] ... we have to do it in a gentle way. If you carry the stigma of an expatient[e] you can't act like a normal consumer advocacy group. If you start yelling... carrying signs, they'll just see it as mentally ill.[f] So that's how we progressed. By being very patient, and gentle, with each other and society (Ashton 1983).

During a 1983 presentation to inpatients a year later, Ashton presented details of the incident that manifested his growing understanding of the politics of labeling and professional power.

> Ashton told them when ABC members showed up, they found that [studio staff] couldn't secure permission to air their panelists, succumbing instead to pressure from mental health officials who demanded <u>they</u> appear as panelists. He had been allowed to speak [for 10 seconds] ....and the consumer answering phones was given one

that never rang (Field notes October 13, 1983).

Ashton connected events at the studio to a power-play by mental health professionals in collusion with the studio management. The management selected incoming calls appropriate for professionals and also knew which phones would not ring in front of the panelists. Ashton's evolving sophistication about the political nature of advocacy is conceptualized in his comments.

Formation of Second Ring Supporters

This developing wisdom was partly directed toward nurturing alliances with other community support and advocacy groups. These groups represent the second ring in the "social problem-movement" spawned by ABC, with ABC members and Ashton clearly in its core. Groups in the second ring included, but were not limited to: OASIS-Fellowship group;[g] the Manic-Depressive Association;[h] Assertive Community Treatment (ACT) counselors and administrators;[i] the City Rescue Mission;[j] Salvation Army;[k] Adult Foster Care providers;[l] and group homes.[m]

Over time, the strategy of "gentle justice" also brought politicians, administrators, professionals and direct service providers to support the ABC organization. In part, this was pragmatic (ABC did work no one else could or would), but it was also motivated by a genuine concern for the people in their care.

Mauss' model for social problem-movements characterizes these supporters as part of a "sympathetic public" that comprise the second ring of the movement. "They are often influential people whose public support for a movement will help to give it legitimacy and acceptance...frequently well educated and skilled in committee work and other kinds of organizational behavior" (Mauss 1975, 47). These traits apply to gathering ABC supporters.

At this stage of Alternatives By Consumers development, this second ring now included: powerful members of the Michigan House of Representatives mental health appropriations committee and its liberal supporters (Rep. Joe Young Sr., Rep. Debbie Stabenow, Rep. Dave Hollister), current and former Directors of the Michigan Department of Mental Health (Pat Babcock and Dr. Frank Ochberg, respectively), and lawyers advising the organization on a no-fee or low-fee basis. Case managers and a few therapists from Community Support Services, direct care workers from the local hospitals, and a sprinkling of administrators from the Community Mental Health Board office can also be included in ABC's second ring of support.

This "sympathetic public" was also comprised of people who publicly acknowledged the work of ABC and Ashton. By 1982, the efforts of Ashton and ABC participants had become noticeable in the larger community. In his capacity as volunteer ABC Director, Ashton's reputation as a man of "unbridled compassion"[1] grew, as did the intensity and out-reach of his work. In the spring of the year, he received two citations for his

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[1] Millicent Lane. "Honor Grows Out of Unselfishness," Lansing State Journal. April, 1982, p. 1B.

work with ABC, the "Jefferson Award", sponsored by WILX-TV and the American Institute for Public Service;[n] and the "Tri-County Distinguished Volunteer Award."[o]

Affirmed by community recognition, ABC's continuing advocacy efforts affected nearly all direct services to mental health consumers. One area targeted for action concerned a local sheltered workshop to which Vocational Rehabilitation Services (VRS) and Community Mental Health (CMH) providers refer clients. Ashton spoke to the local CMH Board's Planning and Policy committee about his concerns. He believed, and consumers sent to the workshop confirmed, that it was an inappropriate placement for people labeled "mentally ill." (The program was originally designed to serve other clients, people deemed mentally retarded, or developmentally disabled.)

Responses to ABC Advocacy Efforts

Following his appearance at the CMH committee meeting, workshop administrators warned Ashton that his interference would "destroy" their program. In an obvious effort to coopt Ashton, they treated him to lunch, and asked that he serve as a liaison between the consumer population and their center. Ashton failed to be coopted:

> At the meeting ....I said if they could show me another way to advocate for new programs that will allow us to grow, without using your program as an example ...I'll do

> it. As long as MI's[1] are ...here and they feel it's demeaning, terrible and destructive to them, I'll con tinue.... They wanted to know why they hadn't heard from me before. I said ... it's my responsibility to motivate the individual to advocate on behalf of him or herself....It isn't important you know who I am.... Nothing changes if individuals don't speak out...(Ashton 1987).

After the affair with the workshop administrators, and in recognition of the political nature of his work, Ashton began to attend the Community Mental Health (CMH) Board meetings more often. This excerpt from my 1983 field notes demonstrates the positive effect of his increasing visibility for ABC concerns:

> When Steven got off the phone...he said: "Two years ago they didn't want me anywhere around. Now..." I asked him what he meant....'I went to this meeting yesterday with (a volunteer) and we stopped at a restaurant... Four CMH Board members came in and recognized me from "somewhere." I told them I was from ABC [and that we received CMH funds] ... but they didn't know what we really did. We got to talking...and they were very interested and wanted ... me to join the Board. They just told me they're sending an application' (Field notes ABC Office, 11/3/83).

Ashton could not be a member of the Community Mental Health Board; it was decreed a "conflict of interest," due to his receipt of CMH funding. However, the rapid manner in which CMH Board members move to include Ashton in their number speaks to an appreciation of their shared interests in aiding the population of mental health consumers. This can be seen as a cooptation effort:..."gestures in the direction of meeting and neutralizing the movement's criticisms, combined with a

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[1] "MI's" is the jargon used by mental health system personnel to refer to the population of mental health consumers (i.e., "the mentally ill"). Ashton had not yet dropped this term from his vocabulary.

propaganda effort emphasizing those interests and values which the society shares with the reform movement" (Mauss 1975, 60). However, the simplistic determinism in Mauss' conceptualization of cooptation does not acknowledge latent issues which the CMH Board members' invitation to Ashton suggests.

The CMH Board members had recognized Ashton from "somewhere." When Ashton connected this for them, i.e., he had been seen at CMH Board meetings, they connected him with a segment of the mental health consumer population that he represents, predominantly working class and low income consumers.

This segment has long presented special problems for CMH Board service providers, whose appellation for that segment has varied from people deemed "chronically mentally ill," to the more current label, "most-difficult-to-treat." Either term belies the ineffectiveness of treatments provided. Ashton's affinity with such consumers is arguably apparent in his presentations, including those to the CMH Board. By offering Board membership to an "expert" in servicing the population with whom they have the most difficulty, two things occurred simultaneously. They legitimated Ashton's work and sought a means to attenuate some of the professionals' stress involved with service to this segment of the consumer population.

Although it seems unlikely that this latter idea was a conscious intent in their offer, other events in the organization's history reflect this unintended consequence for both entities. Professional stress and/or work-load is attenuated through referrals to ABC; ABC participants' stress in handling referrals then intensifies. (This is most clearly seen in the

"ECT incident," described later in the chapter.)

Other subtle cooptative efforts can be seen in day-to-day office operations. Frequently, members of the CMH Board called the ABC office asking for advice. Ashton also informally conferred with the Director of the Department of Mental Health. Reliance on Ashton's expertise allowed the distance between professionals and "most-difficult-to-treat" clients to continue. However, this communication bridge to the professional world also facilitated the next important development for ABC.

In February 1982, the Department of Mental Health (DMH) requested funding proposals for "consumer-run alternative services projects." The announcement memo indicated kinds of assistance DMH could provide to "make the projects successful" and the eligibility requirements for projects. Although the language of the memo stressed cooperation between consumers and local CMH Boards, were it a planned strategy to coopt consumer groups in the state, it could not be better disguised:

> There will be a pre-proposal writing meeting at which interested groups can get questions answered and receive technical assistance in writing the project and designing its evaluation; ... Every attempt will be made to assist in the evaluation process so that it is possible to document the projects' successes in ways which can support replication in other locations. ... We anticipate supporting <u>only</u> those projects which demonstrate clearly the mutual participation of consumer group(s) and a Community Mental Health Board (service or program). These projects are to be <u>consumer-run</u> with CMH assistance. ... The Department of Mental Health is as interested in the process used to develop consumer-community mental health linkages

as it is in promoting some specific service ... [1]

Ashton participated in the workshops offered by DMH, and prepared the "Help Project" proposal which formalized the activities the members pursued informally. Activities named in the proposal include: ABC inpatient visiting; crisis intervention; one-to-one problem-solving; referrals to essential resources (shelters, clothing, the food bank, therapists, doctors, dentists, lawyers); phone service for incoming and outgoing calls; off-site advocacy with consumers at commitment hearings, benefit reviews, probate or criminal court; mediation with rental agents, therapists, hospital personnel as requested by the consumer; help with moving; and other activities identified as needed by consumers trying to maintain community residence and avoid psychiatric hospitalization or readmission.

By October 1982, ABC was awarded a one-year grant by Department of Mental Health, to be administrated by their local Community Mental Health Board in a joint (CMH-DMH) funding arrangement. The disbursement of the CMH-DMH $10,000 grant was delayed, and tight cash flow problems impelled ABC members to start a weekly "Bingo" in November 1982 as a fund-raising effort. Second ring supporters again provided financial help: Michigan Association for Emotionally Disturbed Children (MAEDC) supplied a loan needed by ABC for the first

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[1] Michigan Department of Mental Health, January 21, 1982, Memo To: Regional Directors; Community Mental Health Boards; Consumer/Advocacy Groups; From: C. Patrick Babcock, Acting Director; Subject: Consumer-run CMH Alternative Services Demonstration Projects, pp 1-2.

jackpot of the bingo game.

Promise of funding and formal recognition of Alternatives By Consumers' volunteer program as a DMH-CMH monitored project moved them into the third stage of social problem-movement, institutionalization.

Stage Three: Institutionalization, 1983-present

Within this third stage of Alternatives By Consumers' natural history, there are apparent subdivisions that order the progression of the organization through time. The first is the period during which it received promised funding for Help Project (March 1983); the second period coincides with receipt of funding for a drop-in center (June 1985). The third change of focus came when ABC received additional funds by allocation of the Michigan legislature (November 1985). Following this vote of confidence by legislators, the Department of Mental Health Research and Evaluation division, monitoring all consumer-run alternative service projects, strove to accommodate the needs of the new program, OUR (Our Unified Rehabilitation) Project.

Focal Point: Help Project

In the spring of 1983, ABC received its first funds under the October, 1982 grant award for the Help Project. They began a 6 week formal training program for volunteers, under the auspices of Community Support Services, an outpatient adjunct to the local Community Mental Health Center. Several ABC members, including Ashton, participated but voiced many criticisms of it. One ABC Board member recalled the volunteer training in a 1983 interview:

> After the [structured volunteer] training, everyone but [Ashton and one volunteer] got sick or quit ... people were even hospitalized. ... In a few cases you could see it [related to the training]. They just were real enthusiastic. They wanted to do it, and then they got there and realized there really was more than they were capable of handling. ... They're still part of ABC. They come for support. But they're not really active volunteers.... I don't think [that kind of training] is appropriate. The selection process for it was not very good. We were kind of desperate then.... You have to ... remember that everybody in the organization is--or has been--a mental health consumer and the stress... Well, you just have to be real careful (Willis 1983).

After these experiences, Ashton and the ABC consumer Board decided that formal, structured training was inappropriate for ABC members.

The increased Help Project activities of ABC within the Center of Handicapper Affairs (CHA) building, where Ashton still rented his small office, caused consternation among some CHA staff. Ashton searched for a new office site and subsequently relocated to a basement office in East Lansing that had two large rooms and a private entrance. They moved their offices in late September, 1983.

The description of their in-office routines below were drawn from my field research with ABC at the time:

> The ABC office is a hub for activities and emergent concerns. Ashton comes to the office --or is in contact with it--5 days a week, although most of his 'hands-on' work occurs in the community.... When he is absent... a small cadre of ABC volunteers staff the phones and handle issues that arise, often selecting certain individuals from the known pool of ABC volunteers·to assist others in nascent crises....As Ashton notes, "Everything is done on demand" (Field Notes ABC office October, 1983).

"Typical" demands were exemplified by summary totals appearing in the ABC Quarterly Activity Report for the period 7/1/83 through 9/30/83:

Project Activities:	
Help with locating housing:	29
Help with SSI/SSD hearings/reviews:	6
Help with Social Security applications:	13
Help with learning bus system:	1
Help with transport to medical apts:	9
Help with legal problem:	7
Help with finding professional mental health provider:	8
Help with job hunting, information/support:	6
Help with Vocational Rehabilitation, problem solving/information:	2
Help with moving, one residence to another:	2
Referrals to Food Bank:	4
Peer support for life problem-solving:	140

Quarter Summary Totals:	
In-office (only) volunteers:	24
Help Project volunteers :	19
Referrals to ABC from Community Mental Health agencies:	29
Total # individuals assisted:	146

The activities indicated the breadth and depth of ABC involvement with consumers in their interface with the system. The exigencies these activities redressed also illuminate the quality of daily life for many public mental health consumers.

Expanding Advocacy Efforts: ABC's Orbit of Influence

During 1983 and early 1984, Help Project advocacy efforts continued on a one-to-one problem-solving basis with consumers. Interactive, educational presentations by Ashton and other volunteers, seeking to draw attention to the needs and demeaned social position of consumers, also continued in the community. Presentations were conducted for the Mental Health Appropriations Committee of the Michigan House of Representatives; Community Support Services (CSS) personnel; and to inpatients and staff at one community hospital whose admissions routinely came from CSS therapists.

Unscheduled advocacy efforts also educated an important segment of the larger population, judges in courtrooms.

> I ... was in criminal court, or probate court or a commitment hearing with so many people, so many times representing ABC...that judges began to educate themselves [about] treatment being provided [in state or local hospitals] and the [over-use of] medications ... That visual presence, just ABC being with people, ... was a strong force... (Ashton 1987).

The Alternatives By Consumers orbit was also broadened by their connection to Department of Mental Health (DMH). As a state funded consumer group, ABC was asked to attend a DMH conference involving all consumer-run programs in Michigan. The "consumer conference," as the DMH sponsored event has come to be known, has changed over the years, in large part due to the influence of Ashton. Ashton's response to the first conference stimulated his later efforts to improve the interactional quality of these conferences.

> "I can't do these meetings anymore...it gets me too frustrated. ... They aren't really consumer-run programs. They're programs that non-consumers <u>impose</u> on consumers. There isn't even another Board for any group that's just made up of consumers.... Look at all this!," pointing to a DMH notebook of consumer-run programs. "This is just ... another system consumers have to deal with ... It just makes it easier to lose them.... When you develop a consumer run alternative it's an alternative to the system. You don't incorporate a bureaucracy in it" (Field Notes ABC Office, 10/27/83).

ABC's experience with the yearly DMH conference solidified their non-bureaucratic approach to programs they later developed and to special events they hosted. Without articulating it, Ashton hinted at an intuitive understanding of bureaucracy and its pitfalls.[p] However, his decision to avoid trappings of bureaucratic organization was conscious. Although the group was small at this time, other consumer programs for "consumer-run alternative service" had been encouraged to incorporate formal structure in their early operations, which ABC resisted.

First Year Evaluation: ABC's Help Project

At the end of their first year of Help Project funding, their joint contract with Community Mental Health and the Department of Mental Health was renewed with an increase; the grant exceeded $22,000. For the first time, Ashton was paid a salary ($10,000). Contract renewal also initiated an official evaluation to determine the project's worthiness for inclusion in a continuation budget.

The report indicated that most of the 562 people using Help Project in its first year were clients referred by local CMH agencies. Help Project served the same catchment area[1] as the hospital providing inpatient care: "This allowed Depart-

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1."Catchment area" describes geographic service boundaries for local Community Mental Health Center Boards. A CMHCB is obligated under the terms of the Community Mental Health Centers Act of 1963 to provide 5 services to clients within these boundaries: inpatient care, outpatient care, emergency treatment, partial hospitalization, and consultation and education.

ment of Mental Health evaluators to compare certain characteristics of Help Project users with hospitalized patients."[1]

Demographic comparisons suggested a basic similarity with respect to age and unemployment rates, but differed on most other factors. More women patronized Help Project; more men were inpatients. Fewer ABC patrons were married, reflecting their higher divorce rates. Inpatients were slightly more likely to be employed, but more ABC patrons were not in the labor force. (This latter finding reflects the 'disabled' status of many ABC patrons who receive monthly disability payments from the Social Security Administration.) A wide majority of Help Project patrons had more formal education than inpatients; most had finished high school, and several had completed college courses.[2] Details of these comparison data appear in Table 10, following.

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[1] "Final Report, Consumer-run Alternative Services: Demonstration and Evaluation Projects, 1982-1984," DMH Research and Evaluation Division, p.13.

[2] My impression, based on employment at ABC (1986-88), is that these demographic data for early Help Project users accurately profile the majority of consumers still using ABC.

Table 10: Demographic Comparisons, Inpatients and ABC Patrons[1]

Demographic Criteria		Help Project Patrons	Inpatients
GENDER:	Women	60.0%	34.8%
	Men	40.0%	65.2%
MARITAL STATUS:	Married	3.0%	17.4%
	Divorced	22.0%	13.0%
	Widows	2.5%	2.2%
	Separated	4.5%	2.2%
EDUCATION:			
7 years or less		2.0%	10.1%
9-11 years		20.5%	60.9%
12 years (H.S.)		54.0%	11.7%
12 years or more		23.5%	17.3%
EMPLOYMENT:			
Employed		7.5%	11.4%
Unemployed		60.5%	68.2%
Not in labor force		32.5%	20.4%
AGE:	22-40 yrs	72.5%	69.6%
	41-60 yrs	20.0%	26.1%
	Over 60	1.5%	0.0%

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[1] Table data are derived from summary Table 1 in the "Final Report, Consumer-run Alternative Services: Demonstration and Evaluation Projects, 1982-1984," DMH Research and Evaluation Division, p.16).

The most dramatic finding in the evaluation report, however, was the assessment of social functioning for the respective sample populations, measured with an instrument called the "Global Assessment Scale" (GAS).[1] The scale is routinely administered to incoming patients and again before their discharge. The scale was also given to outpatients at Help Project by their CMH case managers for the final evaluation report. The findings revealed something about the people using Help Project that ABC members "knew" but could not document: most ABC patrons are high-risk candidates for rehospitalization. Summarizing the findings, evaluators noted that:

> *The distribution of the [Help] project client scores are most similar to hospital admission scores, a time when the lowest functioning level is normally observed;* the distribution is entirely unlike the scores of hospitalized clients at discharge. These comparisons show that *the typical person receiving services from [Help Project] is at risk of being hospitalized.* At such a time, a person's ability to successfully solve the problems of finding housing and interacting fruitfully with public service agencies is absolutely essential to a successful adjustment in community life ("Final Report, Consumer-run Alternative Services: Demonstration and Evaluation Projects, 1982-1984," DMH Research and Evaluation Division, p.13). (Emphasis added.)

This evaluation report, which represents an official recognition of ABC's ability to help consumers who might otherwise be hospitalized stay in community settings, contributed to the Department of Mental Health's continuing support, and expansion of, available funds for consumer-run projects.

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[1] The social functioning categories that the scale seeks to measure include: interpersonal relations; personal care of self; overt manifestations or expressions of psychiatric symptomatology (e.g., anxiety, neurosis, psychosis); coworker relations, if applicable; quality of support network relations, etc.

Focal Point: Drop-in Center

More flexible than structured programs, ABC could initiate activities to fill recognized needs for participants. As volunteers became more active, efforts were made to extend the range of Alternatives By Consumers "socialization" opportunities for members and continue low-key community outreach activities. During holiday periods, when many consumers feel depressed and isolated from family and friends who turn them away, ABC intensified its outreach. On Thanksgiving day, 1983, the "first annual" holiday meal was prepared for ABC members and friends, free of charge (35 people attended). This, and the Christmas day meal that ABC also prepared, became yearly events.

During 1984, Department of Mental Health solicited proposals for other consumer-run programs and Ashton submitted plans for a drop-in center. The idea of the drop-in center again sought to formalize the informal activities of ABC volunteers and staff. It would provide an unstructured setting where peer-support could be emphasized, and staff and volunteers would work together to help patrons avoid rehospitalization during times of crisis (i.e., the center would serve a monitoring function). Light snacks, coffee, books and recreational activities comprised the bulk of tangible opportunities available to consumers who would use the center.

Alternatives By Consumers' track record facilitated a positive review of their plans by funding sponsors. In the spring of 1984, Ashton was notified that funds for the drop-in center would be available 7/1/85. The additional $20,000 grant for the drop-in center's "demonstration period" (i.e., fully funded first year) provided $10,000 for another paid staff position (a drop-in Director), and covered most of the fixed expenses, such as rent, utilities, and phone. Donations from community supporters defrayed some of these costs: e.g., parents of a consumer in the mental health system provided paper products, sugar and cream, and other items used at ABC on a daily basis.

Birth of the ABC Center

In preparation for the drop-in center, a suitable house was found that ABC could afford. Located in an east side residential neighborhood, it is bounded by a major city street on a bus line and fairly close to downtown. The lease was prepared for 6/1/85, and ABC moved. The two story frame house easily accommodated the drop-in center on the first floor of the building, and Help Project activities on the second. The official opening occurred on July 1st, 1985.

Soon thereafter, Ashton was notified that the City of Lansing would contribute $10,000 to the upkeep of the ABC (drop-in and Help Project) Center, providing no grant monies are used for salaries. With grant monies promised (the total ABC budget was now $52,000), the Bingo fund-raising effort ended in June, 1985.

Although Alternatives By Consumers did not have an "official" drop-in center prior to receiving funds for one in 1985, the Help Project office usually doubled as a drop-in site for consumers. The benefits to consumers who used the ABC office when they needed to be with people who were supportive and accepting of them while in the throes of an emotional crisis were apparent during this "double duty" Help Project period. This experiential insight was part of the impetus for submitting a funding proposal for an ABC drop-in center. But Ashton also saw its need on a wider scale.

In this regard, Ashton sought permission to appear before the mental health committee in the state Congress. In his appeal for more appropriations to fund additional centers, he made a profound impression on Rep. Joe Young, Sr., a member on the committee. Young, Sr. approached Ashton and asked him to write a proposal for organizing consumer groups in other parts of the state interested in establishing their own drop-in centers. A centerpiece of the proposal was that ABC would act as the "consumer expert" to the emerging groups and centers.

With help from Rep. Young, Sr.,'s office staff, the idea took form as a proposal for "OUR Project." The plan was submitted to the legislators for a vote on monetary award. The legislature approved $72,000 for this purpose, to be funneled to ABC through the Department of Mental Health as a demonstration grant under the "consumer-run alternative services" program.

Focal Point: OUR Project

Ashton continued to oversee Help Project concerns, but his time was stretched thin as he prepared for the beginning phase of OUR Project. As soon as the grant funds arrived for the Project in early November 1985, Ashton hired a full-time assistant for OUR office.

Ashton and his assistant earnestly began organizing efforts in Grand Rapids with consumers expressing interest in establishing a drop-in center. Ashton assisted them as they formed a consumer Board of Directors, selected a name, elected Board officers, filed necessary forms to become a recognized non-profit corporation, and identified a consumer able to handle the Director job. Eighteen months later, by the end of 1987, consumer-run drop-in centers organized with the assistance of Ashton and OUR Project staff were operating in: Grand Rapids, Kalamazoo, Benton Harbor, Pontiac, Muskegon and Hamtramck.

Increasing the Division of Labor at ABC

In Lansing, the other ABC programs bustled with on-going activity. In addition to the areas of assistance first provided by Help Project, a wider focus now included transportation assistance and relocation help for patrons of the program. The increase in transportation concerns coincided with the arrival of two full-time volunteers with cars and access to a pick-up truck. City funds were used to reimburse drivers' mileage costs.

The orbit of ABC was broadened again as groups affected by Ashton's work asked to become more firmly involved with the organization. New entrants to the ABC orbit included Michigan State University, the court system of Ingham county, and Vocational Rehabilitation Services.

Michigan State University Nursing School students were given permission to come to the ABC center on a scheduled basis, volunteering help while obtaining clinical credit hours for work with ABC consumers. In recognition of ABC services as official "friends of the defendant" and as unofficial advocates for consumers in court, the Ingham county court established mechanisms with ABC that legitimated referrals for first offenders doing "community service work" at ABC in lieu of jail time or fines. Community Support System (CSS) and Vocational Rehabilitation Services worked together with ABC staff to place a consumer at the Center. Under provisions of the Job Training Placement Association (JTPA), ABC was subsidized for hiring a mental health consumer. In late spring, 1986, a young woman was referred to Ashton for the JTPA position and was hired as an aide to the Help Project.

In April, 1986 Suzanne Turner (a volunteer for the preceding 4-5 months) was hired for Help Project Director, as Ashton realized OUR Project demands prevented his necessary attention to Lansing-based advocacy needs. One of Turner's early projects was an ABC newsletter. The first issue was printed in June, 1986. Contributions for newsletter submissions were solicited from all ABC participants. Turner encouraged people to use the newsletter as a critical forum.

Turner also established a "volunteer transportation coordinator" position for the full-time volunteer who had worked with ABC members, providing rides to needed services and/or housing rental possibilities, etc., for nearly a year.

During the month of Suzanne Turner's hiring, ABC members approached their Community Mental Health Board, seeking funding for a "transportation coordinator" position. They hoped that the full-time volunteer helping in this area since the center opened could be hired. Despite their presentation of 125 mental health consumer signatures on petitions, the fiscal position of the CMH Board could not cover the extra expense, and their request was denied. Undaunted, the volunteer driver continued to offer his services to Help Project on a full-time basis under the reimburse-for-mileage provision established earlier.

In June, 1986, I reentered ABC's orbit, volunteering help where it was needed, mostly in the drop-in and Help Project areas. In September 1986, I accepted employment with the OUR Project. As organizing efforts with consumers around the state intensified, a part-time consumer employee was hired for OUR Project in April, 1987. When the budget for 1987 was revised to allow the part-time position to expand, Dana Monroe was hired on a full-time basis in October, 1987, as a Project Aide.

Opportunity for ABC Volunteers

Suzanne Turner resigned as Help Project Director in October, 1986. During her work at ABC, she developed special interest in advocacy issues concerning state hospital patients. Her resignation allowed her to accept employment at a federally funded advocacy agency. In the same month, a woman involved with the ABC newsletter as editor/illustrator was hired for full-time Help Project Director. Alice Wetherby began work in this capacity April 13, 1987.

In May, 1986, ABC volunteers were honored with the "Jefferson Community Service Award," once bestowed on Ashton during the early ABC years. They were nominated by a voluntary mental health association for their dedicated service to the vast population of consumers using the ABC center and its services.

OUR Project Relocation: Ripple Effects of Change

The growing user census for the Help Project and drop-in center brought increased noise levels and unplanned work interruptions in its wake for Our Project staff. This provided impetus for the relocation of OUR Project headquarters to an office complex in November, 1987. The drop-in and Help Project continued to share the two-story house in Lansing, although staff and member anxiety over the relocation was soon apparent.

Several times a day, the Directors of the ABC programs called the OUR Project office for advise over matters that heretofore they handled alone. Ashton addressed concerns by establishing a new routine, sharing coffee with others around the big table at the ABC Center every week-day morning before going to the OUR office. While the number of calls to OUR Project office from ABC Center staff remained significantly high in the last two months of 1987, Ashton's new routine seemed to ease some of the anxieties generated by the move. In

1988, the effect of the OUR Project relocation abated. Staff and volunteers at the Center again concentrated energies on meeting needs that consumers presented to them in respective ABC programs.

National Recognition for ABC; A New Adventure for One

In February, 1988, the Help Project Director was invited to attend a National Institute of Mental Health-sponsored conference on the "homeless mentally ill," and traveled alone to Washington, D.C. to give a presentation on Help Project activities in this area.

The trip represented a personal victory for Wetherby, who had been previously unable to travel to unknown places alone. She named two factors which allowed her to assume this risk: more self-confidence corresponding with peers' recognition and appreciation of her Help Project work; and loyalty to ABC ideals and advocacy efforts, which she wanted to advance (personal communication, ABC Center, 1/5/88). Wetherby's trip also represented an organizational victory for ABC, as national recognition amplified its realm of influence.

National Institute of Mental Health (NIMH) had learned of ABC's existence through the Michigan Department of Mental Health. Official recognition of ABC's work and prowess in consumer affairs had prompted the invitation (personal phone communication, NIMH representative, December, 1987).

Exemplar of ABC Advocacy: Accommodation, Stress and Fall-Out

In March of 1987, the Help Project received a referral from Community Support Services (CSS) requesting transportation for an individual receiving a series of electroconvulsive therapy (ECT) treatments in a Lansing hospital. The Project Director expressed concern over the possible appearance of ABC support for the treatment if transportation was provided.

When concerns were broached to CSS personnel, they arranged an in-service training meeting about ECT at the local community hospital where the treatments occur. The Help Project Director, Alice Wetherby, Ashton and I attended the session. Below, Wetherby describes her understanding of these events in her quarterly report to funding sponsors for that period. The excerpt is long, but it encapsulates the tension this issue evoked among several ABC staff and volunteers. It also exemplifies the stress involved in accommodating professionals' views of treatment in the face of contrasting experiential knowledge.

> Another hot issue has come up involving ECT. ... [ABC] staff were given information about ECT to read[1] and there was an in-service set up for us by [2 psychiatrists and 2 staff from CSS]. Dr. DeMello [a psychiatrist] administers ECT to people at Ingham [Medical Center]. They showed us parts of a video on ECT and there was also discussion. Dr. Bowden [a psychiatrist] said he had witnessed an ECT session, and had been "let down because it wasn't as dramatic as he thought it would be." That did not change how we feel about it. Some of us are aware of people who had this treatment, and it was productive for them. We are

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[1] The information was supplied by Community Support Services personnel. It was a copy of a *Harvard Medical School Mental Health Letter* devoted entirely to electroconvulsive therapy.

> also aware of people who were traumatized by it, and still are. Apparently, there have been changes made in the procedures through the years, and also ECT is not supposed to be given to someone against their will. I only wonder how much is done to convince someone to agree to such a thing. I do know that this particular woman is easily persuaded. She has told me in transit that she didn't want any more treatments. She still ends up going again and again ([Alice Wetherby] Director, [Help Project] Quarterly Report 3/31/88, p. 4).

In the case of ECT treatments, ABC resolved its conflict by advocating for the person (i.e., offering support and needed transportation) rather than rejecting the referral for transportation help to treatment. In this way, ABC upheld its contractual obligations (i.e., honoring referrals); voiced concern over the treatment; and maintained open communication between the agency and ABC.

This scenario operationalizes the tenets of "gentle justice." The organization advocated for the treatment desired by the person at the time the treatment request was made. In other instances, it supports persons refusing treatments requested by practitioners. In short, ABC advocates for the right of individuals to decide what is in their best interest, then offers support to persons encountering difficulties in those decisions. Ashton believes that this stance, which is accepted by ABC staff and volunteers in their advocacy efforts, serves the end goal of gentle justice.

Neither Ashton nor ABC advocates routinely question how the individual reaches the decision; nor do they customarily reflect on known or probable consequences of that decision. (Exceptions to this latter trend usually involve intervention if decisions would likely result in immediate harm to self or others and/or if people make obviously imprudent decisions during times of psychosis or crisis.) In this instance, advocating for gentle justice precluded the need for ABC to assert a specific position on ECT treatment.

This organizational stance prevented Ashton and most ABC staff from seeing the offer of ECT reading materials and an ECT in-service training session as a cooptation effort. (Although Wetherby's ambivalence, expressed in the quarterly report, suggests the effort may not have been completely successful.) However, providing acritical reading materials which lauded ECT success and conducting an in-service session to inform ABC staff about current ECT procedures (undertaken by the psychiatrist administering ECT) were clearly "ameliorative gestures in the direction of ... neutralizing the movement's criticisms" (Mauss 1975, 61).

The unexpectedly sudden departure of Wetherby in mid-April was a painful reminder of the stress involved in ABC advocacy efforts. Little more than 5 weeks after her risky and successful venture to Washington D.C. for the NIMH conference, her final resignation was submitted. It was less than two weeks after the ECT in-session. One week prior to her resignation, Wetherby had decided to assign a different driver to assist the consumer, in lieu of providing the ride herself. Although her resignation letter did not specifically refer to the ECT incident, it did reflect a self-denigration of her continuing abilities to help others (ABC inter-staff communication, 4/88). Soon after she left her ABC position, coping difficulties overwhelmed her and she was rehospitalized.

New Horizons for the OUR Project

In February, 1988, OUR Project completed its production of "Gentle Justice," an educational video dramatizing events typically occurring at a drop-in center. It also incorporated interviews with Ashton and other community leaders who support the work of ABC (e.g., State House Representatives Debbie Stabenow, David Hollister and Joe Young, Sr.; Director of Department of Social Services, Pat Babcock; and Director of Department of Mental Health, Tom Watkins).

In the OUR Project quarterly report, when the video idea was first contemplated, Ashton described it as a "new strategy:"

> Part of the [OUR Project] mission is not only to educate the public concerning the possibilities and worth of the drop-ins, but also to sensitize people to the myths...about "mental illness." [The video] can be a forum where the "mentally ill" can be seen as persons first, and people with special behaviors second; ... to show the difference between actual symptoms of "mental illness" vs. symptoms that are associated with ...high-dosage psychotropic medication; ...and to state the philosophy behind the centers: ...consumers <u>can</u> ... grow through the experiences they've had and share that growth with other consumers ([Steven Ashton], Director [OUR Project] Yearly Report, 12/31/86, pp 6-7).

The video was used for presentations to Community Mental Health Boards and clinical staff, consumers, parents groups, and at the yearly DMH-sponsored "consumer conference" for consumer-run alternative service programs. It has also been used with college students in social work programs, to educate them about the role drop-in centers play in consumers' rehabilitation. Production of the video and its use in a wide variety of community settings reveal the vanguard nature of Ashton's work with mental health consumers.[9]

Organizing work continued in OUR Project during February and March of 1988, with consumers expressing interest in drop-in centers for more rural areas, the upper peninsula and "thumb" area of the state. These endeavors opened new experiences to Ashton and OUR Project staff, bringing the need to develop strategies for organizing and implementing the drop-in program in non-urban areas to the fore.

Efforts to expand consumer-run alternative service programs to these areas met with ready approval from the funding sponsor, Department of Mental Health. Rather than attempting to repress efforts to expand the "social-problem movement," which the Mauss model postulates as one of two predictable responses at this stage of ABC's history, representatives from DMH sought funds to allow the expansion on behalf of Ashton and OUR Project. The other predicted response, social institution actors' efforts to coopt movement members, does not describe these activities, either: the autonomy of movement actors and possibilities of growth were enhanced by DMH administrators' successful attempts to secure additional funding.

In April, 1988, Ashton was once again confronted with staff turnover. Wetherby tendered her resignation as Help Project Director during April and my notice of resignation became effective in June. Two suitable replacements for the positions were hired, and began work in May. My last month as Associate Director coincided with the first month's employment of my successor, Martha Wright, a former volunteer for ABC.

On-Going Stress: Economic Woes

Sudden and unexpected loss of the City of Lansing $10,000 grant in June, 1988 caused drastic cut-backs in transportation help to ABC consumers and much consternation over the future of the drop-in and Help Project programs. Ashton advocated for the restoration of the grant with a letter-writing campaign to the Governor, the Mayor of Lansing, the office of Human Resources within the city government that administered the grant, and by appeal to high placed officials at Department of Mental Health and Community Mental Health to support the reclamation effort. The city budget was reviewed following these appeals, and a portion of the grant ($7,500) was restored to the organization.

Although this restoration of funding to Alternatives By Consumers might constitute another instance of the host society's cooptation of the organization in Mauss' terminology, it was not without its contradictions. Can cooptation be seen as a strategy by the host society when it serves the ends of the society and also maintains the autonomous nature of ABC's programs? This question, and other tensions in the stage analysis model will be considered in the following section.

Critique: The Social Problem-Movement Model

It is somehow appropriate to end the stage analysis at a point when funding issues have again caused much turmoil to Alternatives By Consumers. The response of city sponsors to advocacy efforts to reclaim the grant may have been as much a response to the ABC-initiated appeals to other administrators (i.e., the Mayor, the Governor, the Director of Department of Mental Health) as it was to the ideals of the "social problem-movement" which the group represented.

It is this blurring of boundaries that has been characteristic of ABC's situation through time. While their projection of identity as a group advocating "gentle justice" is upheld, and their programs are largely autonomous despite funding contract requirements, their constant interface with professionals of the system has shaped the evolution of the group. It is not possible, for instance, to map linear effects of their advocacy. Many efforts affect only individual consumer situations. It is often difficult to identify responses from institutional actors in the host society which are directly attributable to effects of ABC consumer advocates' actions, save on a case-by-case basis.

Neither is it clear that the entire range of response from the host society to ABC can be subsumed by Mauss' argument that a social problem-movement's natural history is "dependent primarily upon the ... particular <u>mixture</u> of cooptation and repression applied by the society, and by [the movement's] own manipulation of, and responses to, that mixture" (Mauss 1975, 59,61).

Offers of funding and use of the ABC-developed drop-in center as a model program can be assessed as cooptative efforts, in the sense that including ABC in system efforts might quell its criticisms of the system. Funding the group as an adjunct to the system lessens possibilities that consumers interested in attending ABC or its affiliates will leave the system entirely. Federal funds for Community Mental Health Centers depend on demonstrating that Centers are providing necessary services to persons in their catchment area. However, there is another quality to those interactions that eludes the concept "cooptation."

Part of the difficulty in applying the Mauss stage model to this group's natural history is that the model itself is bounded by unwitting assumptions made about the actors who will be involved, the functional role of social institutions for social movements, and the static conceptualization of social structures as they affect situated actors, e.g. "champions," leaders, movement members/supporters, and "host society" institutional representatives. Many of these assumptions are characteristic of the structural/functionalist theories which inform much social problem and/or social movement literature. Application of a conflict perspective to issues raised by the Mauss' theoretical model, which encapsulates much of this literature, illuminates some of these unexamined assumptions.

Ashton upheld some, but not all, of Mauss' conceptualizations of champion, i.e., people who "in their own interest, attempt to influence public opinion and the collective definitions of reality and who thereby generate social problems via social movements" (Mauss 1975, 11). It was demonstrated that there are elements of self-interest in Ashton's development of the organization Alternatives By Consumers. He is paid by the organization and its advocacy efforts are aimed at alleviating perceived injustices in the mental health system. This affects Ashton, as well as the population of mental health consumers, since he still receives services from the system (i.e., psychotherapy). He is also devoted to altering the collective definitions of reality typified by the normative understanding of "mental patient." Moreover, he is self-consciously aware of his ability to influence consumers and the larger public and pursues opportunities that will allow him to do so.

It is less clear, however, that Ashton has "generated a social problem via a social movement." He has rather named the problem in existence for decades in the U.S.: ineffective care for people labeled "chronically mentally ill," and ignorance of their plight in the community. The a priori assumption of the model, that the movement work generates a social problem is not upheld in this case. The work of ABC as a social movement offers pragmatic and ideological redress to an existing problem. In effect, it purports a social solution. "Gentle justice" is first achieved when "mental patients" are accorded human dignity and secondly, when consumer-run programs are supported that lead to empowerment (at best) and humane care (at least).

This case study contradicts tenets of the Mauss model in other ways as well. While some instances are simply departures that can be expected when actual events are compared to a postulated 'ideal type,' other departures from the model suggest that static conceptions of class structure or the function of certain social roles do not fully account for movement activities and/or societal responses that are anchored in contested relations between the respective actors.

For example, to Mauss (1975, 52), leadership emerges from the middle and upper class strata of the society _because_ this class position connotes availability of time, energy and resources that can be devoted to the "cause." In contrast, Ashton's physical disability was the impetus for subsequent availability of time, energy and resources. When unemployment benefits were exhausted and supporting disability benefits denied, this provided unencumbered time _and_ exposure to conditions in the mental health system faced by most other working class and/or low income consumers. In Ashton's case, it was a _lack_ of resources that lead to identification of the problem area and time to pursue advocacy toward solution.

However, there are elements in Ashton's class and status position that did facilitate his volunteer work as a leader for the "incipiency stage" of the ABC movement. These elements are similar to those that allow "middle and upper strata" to assume leadership positions in society. Mauss (1975) cites this conceptualization by Oberschall (1973) to characterize social problem-movement leaders:

> It is difficult to escape the conclusion that the upper and middle strata in society supply the substantial bulk of opposition leaders to all manners of social movements in proportions far above that of their percentage in the population at large. But this is equally true for political leaders in... parties and in other institutional groups... (Oberschall 1973, p.5, in Mauss 1975, 52).

This conceptualization masks class and status position relevances that contribute to disproportionate numbers of leaders who emerge from the middle and upper strata of society.

For instance, there was another income source for the Ashton household from his wife's employment. Thus, Ashton's unemployment was buffered in part by this resource. The household income fell, but it did not jeopardize housing nor provision of essential commodities such as electricity, heat, clothing or food. Moreover, as the male head of household in a traditionally structured family, the unpaid domestic work of the wife (child rearing, food preparation, etc.) partially contributed to Ashton's out-of-home availability for ABC work. Moreover, there is a lack of racial or ethnic barriers to his work with the predominantly Caucasian consumer population that ABC services. This is also true of his work with the predominantly Caucasian professional-administrator stratum with whom Ashton and organizational actors interact.

These same features are the unspecified buttress for research which show leaders of U.S. social institutions are predominantly white married men. Here we see that a traditional institution, family, provides not a response to the movement, shaping its natural history, but a support for it. Institutionalized racism also supports Ashton's emergence as a leader, and it is plausible that institutionalized sexism allowed a more positive evaluation of Ashton and the organization's work because a visible male leader is normatively appropriate and valued.

When Mauss says that the host society "makes its moves through traditional institutions...government, business, churches, families" and that "normally the traditional institutions of society can be expected to resist the reforms called for by the social problem-movement simply by generalized inertia, apathy or hostility" (Mauss 1975, 59-60), he is referencing the actions of people in these institutions to the reform movement program. This reductionism discounts the support that traditional institutions unwittingly <u>offer</u> such movements.

It has not been apparent that Ashton's work as leader of Alternatives By Consumers has involved the type of compromise to attract members that Mauss suggests are typical to social problem-movements: "a movement to be effective usually has to make certain pragmatic compromises in order to attract as much support as possible" (Mauss 1975, 59). He credits this dynamic as the reason: "the movement must try to get as many members as possible into the outer and middle circles without sacrificing the commitment and zeal of the membership in the core circle" (1975, 59).

This portrayal of membership relies on another unexamined assumption. There is no theoretical awareness in the model that a social movement organization can grow from the bottom up, and not just be led through its stages by the top down, i.e., by the leader pulling its weight along behind him or her. The interactive effects at work may not be only between the movement and the host society: changes may come into the organization through the work of its membership, in interaction with each other as well as the larger community. The model, then, also embraces the professionalist bias endemic to U.S. social structures, but particularly characteristic of the mental health system.

This is not to say that leadership style has not affected the growth of Alternatives By Consumers and its supporters. But by Ashton's own reports, he discovered his leadership ability in the context of interaction with other mental health consumers who had similar experiences. The interactive effects of his work with peers stimulated further development of his leadership. Although he is unlike many peers who could not tolerate the public scrutiny that accompanied his leadership efforts, it is not possible to determine that he would have become ABC's founder <u>without</u> the constant interaction with other people labeled in psychiatric terms.

In this case study, it appears that people were first brought into the rings of support because Ashton appealed to their sensibilities in a charismatic fashion <u>and/or</u> by virtue of pragmatism. As the organization evolved, Ashton's influential role with individual participants at ABC lessens. In their stead, new interactions between participants arise, but continue to typify the quality of interaction Ashton discovered in relationship to members of the early ABC community. Participants who invest substantial amounts of time and energy in ABC activities learn to propose alternative definitions to *each other*. This development, no longer bound to Ashton's presence or sole example, is the bedrock of the supportive community that ABC represents. (Social relationships at ABC are more fully analyzed in Chapter 8, "ABC Experiences.")

The concept 'charismatic fashion,' as applied to Ashton's influence, is meant to encompass reactions of consumers, who could establish an experiential identification with him; reactions of parents and friends of consumers who vicariously understood the positive changes Ashton and the organization worked toward; and reactions of some of the direct care workers (e.g., hospital staff, therapists, case managers), whose position allowed them close contact with consumers and who could also vicariously understand what treatment changes would mean to those in their charge.

A pragmatic appreciation of Ashton's work drew supporters to the movement from the mental health system. Professionals and administrators appreciated the cost-effectiveness of the ABC programs and the credibility of its leader. Professionals might be more likely to appreciate the on-going peer support available for consumers at a drop-in center and less likely to fully embrace the idea of peer-counseling occurring at such centers, having an interest in maintaining the professionalist ethos of the system. Administrators might emphasize an appreciation of the "ease" with which a program like a drop-in center might be replicated in other parts of the state and less likely to appreciate the totally unstructured nature of a drop-in program, as evaluation might be more problematic under those conditions. Both strata, despite variations in emphasis, wholeheartedly supported a program whose final evaluation demonstrated benefits to clients and cost-effectiveness.

Other unexamined assumptions in the social problem-movement model are contained in the idea of cooptation and repression as ends of a reaction continuum from representatives of the host society institutions. Cooptation and repression are strategies of a ruling class. They depend on the notion of a social inequality, where the powerful can deflect the potential impact of social disruption through direct force (repression), or by reward (cooptation). Power is not seen as a dialectical, contested relation. The structural-functionalist model cannot accommodate notions that social problem-movements may have an enduring effect; the posited unilateral idea of power predicts that social-problem movements will become fragmented and suffer demise, regardless of objective conditions in the social world actors' occupy.[1] The long stage of institutionalization that ABC has enjoyed counters the implicit theorized notion that people in a social movement cannot have a lasting impact on objective conditions that create and/or maintain the social problem they seek to redress. In fact, the impact of Alternatives By Consumers' advocacy efforts to develop consumer-run alternative services for traditional mental health care continues to grow. OUR Project satellites in urban and rural settings, national recognition, and program modeling after these ABC efforts expand their realm of influence. The social landscape of traditional mental health services is substantially changed by

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[1] "...No objective change is needed in putatively problematic social conditions to make the life cycle [of a social problem-movement] run its course" (Mauss 1975, 66).

these activities.

At the same time, casting members of a social problem-movement as unilaterally less powerful infers that they will manifest a divergence of interests from those in power positions. Such notions do not well explain the *convergence* of interests that this case study has presented. This convergence points to a similarity of interest masked by the model's simplistic dichotomy, those able to coopt or repress versus those without such sanctions.

The parties most responsible for Ashton's receipt of funding, administrators and division managers in a state funded bureaucracy, Michigan Department of Mental Health, may be in a more powerful position than Ashton, but their interests are not necessarily subsumed by a ruling class rubric. Rather, they occupy "contradictory class locations" (Wright 1975) in the capitalist class structure that affect their political and ideological relations. Neither bourgeoisie nor capitalists, they can embrace Ashton's ideas because they share a similar political and ideological conviction that social change must occur in the system of mental health care. Their economic interests are not jeopardized by an interest in social change. It is the *degree* to which this interest in social change is shared that differentiates Ashton from administrators and professionals.

Moreover, Ashton's promotion of an organizational stance (i.e., gentle justice) that supports individuals desiring available treatments thought viable in the care system quells any threat to the system itself. In this stasis, the interests of Ashton and administrators converge. Were Alternatives By Consumers to become less supportive of treatments available in the system and more vociferous in demand for consumer-run treatment funding, it is plausible that the respect relations currently enjoyed between Ashton and administrators might well become antagonistic as ideological and political interests disturb the balance.

It should not be overlooked that the interests of administrators in the system status quo are unchanged by their embrace of Ashton as a consumer representative. Despite similarities to his consumer peers, Ashton is also unlike many of his mental health consumer peers. His treatment experiences are somewhat similar, and the damaging effects of stigma are as harmful, but unlike most others, he is verbally articulate and successfully intuitive in his "gentle justice" approach to advocacy. By demeanor, he approaches system representatives as a peer.

In large part, he is a "known" commodity in the system: he is middle-aged, Caucasian, literate, an urban dweller, and able-bodied. These descriptors apply to the majority of community mental health system clients today. Their inverse (i.e., racial or ethnic minority members, children and the elderly, illiterates, rural dwellers, physical handicappers)[1] describes categories of people least likely to be seen in the system and more likely to be treated by ABC or one of its satellites.

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[1] These findings are reviewed in Brown (1985, 5).

Thus, Ashton is able to establish personal relationships with system administrators, providers and other professionals because he is someone with whom they can interact in known ways and because his work with the "lost" segment of consumers is successful.

The personal relationships that develop between system representatives and Ashton constitute another facet of the social structure that articulate the situation of ABC in the institutional matrix. In practice, these interactions cannot be explained by actors' adhering to set role prescriptions (e.g., movement leader or system administrator), because the interface is more complex than that. The social system affecting the movement and the mental health care sector is defined and reproduced by the quality of the exchange. As Giddens points out,

> It is fundamental to affirm that social systems are not constituted by roles but of (reproduced) practices; and it is practices, not roles, which have to be regarded as the 'points of articulation' between actors and structures (Giddens 1983, 117).

Giddens' insight allows a focus on practices as an important component in the articulation of actors and social structures. As the quality of exchange with system representatives reproduces that bureaucratic system, other practices of ABC impel change in the social system. In these practices, the tension and paradox of ABC's position within the institutional matrix are revealed.

The most effective practice in ABC participant interactions is the operationalization of "unconditional acceptance" of people using ABC programs. This is part of the philosophy represented by "gentle justice," that all people should first be accorded human dignity and spared judgment by their peers for their problematic actions or behaviors. Inherent in this stance is an anti-bureaucratic ethos.

The structure of a bureaucratic capitalist society is premised on the notion that the "client" is subordinate to the bureaucrat (Ferguson 1984). In programs designed to equalize status and eliminate judgment based on assessments of inferior-superior characteristics, empowerment is the highest objective. In this interest, bureaucracy is eschewed. As Ferguson (1984, 82) points out in <u>The Feminist Case Against Bureaucracy</u>: "self-examination ... and a commitment to self-knowledge ... is simply not possible in bureaucratic language."

Thus, unconditional acceptance allowed by "gentle justice" makes a "case against bureaucracy" similar to that made by feminists. Traditional practices in bureaucracy posit clients as the subordinate in the same ways that traditional practices in the social system (e.g., institutionalized sexism) posit women as subordinate. In the refusal to oppress people labeled "mentally ill" by judging them inferior, healing occurs. As peers meet as equals, form relationships and pursue activities together, self-esteem regenerates. When acceptance is accorded by others, the person internalizes the belief that he or she is acceptable. This is the necessary first step to empowerment. Small group consciousness raising for women parallels the development of programs embracing unconditional acceptance. Like women's groups, there is recognition in ABC programs that the "personal is political," and that the political oppression ascribed to (women and) people labeled "mentally ill" must follow anti-bureaucratic routes to empowerment. Thus, an anti-bureaucratic ethos can loosen fetters of oppression for "mental patients" in ways analogous to those realized by participants in the women's movement. The community realized by women who join in efforts to alter social processes which demean and oppress may also be realized by consumers striving to achieve similar goals.

This highlights another tension in the ABC position in the institutional matrix, specifically in the practices of Ashton and his relations to system bureaucrats. ABC programs are anti-bureaucratic, but the continuing discourse must occur with bureaucrats in control of resources essential to the group. This relates to the question of whether cooptation can apply to a funding situation that results in social movements' program autonomy. Can empowered people be coopted? Will the bureaucratic discourse, which eschews self-reflection, silence the discourse of empowerment <u>allowed</u> by the bureaucracy?

The case study of Alternatives By Consumers suggests that neither cooptation nor repression nor necessary participation in bureaucratic discourse has silenced the voice of consumers who will be heard. Practices of ABC advocates afford opportunity for consumers to create genuine communities where healing can occur. Their advocacy efforts do not alter specific treatment practices within the system (which continue to oppress many consumers), but their work benefits the system by inexpensively extending its territory through successful outreach to consumers who have not benefited from traditional treatments.

Thus, we find that the theoretical tenets of Mauss' model of social problem-movements do not fully capture the essence of Ashton as leader nor the intentions of ABC and mental health system actors. There are ways in which the model captures peripheral dynamics; the notion of a stage progression does apply to ABC. And the question of whether the movement is shaped by interaction with the host society also has obvious relevance, although not in the determinist, reductionist manner Mauss depicts. Through the imposition of the model on this case study, flaws in the theory have been uncovered which suggest other factors are more salient in attempts to portray the natural history of ABC. It is through close attention to the *meaning-making* talk and activities of actors; the *objective conditions* that impinge on situations of actors; and the *intention* of actors in interaction that allow the point of articulation between actors and structures to be seen: in practices which reproduce the system and practices which change the system.

Many of the unexamined assumptions in the model are the very same that are encompassed in contemporary mental health treatments, leading in the first instance to inadequate theory and in the second to inadequate healing. A model predicated on normative social practices (sexism, racism, classism, professionalism) sheds little light on a consumer organization challenging normative definitions of "mental patients" as incapable and "mental illness" as incurable. In the same way that flaws of theory directing a stage model are revealed by attending to actors' talk and meaning-making activities, flaws of treatment practices are revealed by attending to the talk and meaning-making activities of actors participating in such treatments. The next chapter is devoted to an examination of these issues.

CHAPTER END NOTES

(a)The demise of this group coincided with Ashton's waxing role in the Department of Mental Health's consumer-run demonstration project and Ochberg's resignation from DMH.

(b)Staff Writer. 1981. [Alternatives By Consumers] Member Pamphlet (Privately reproduced).

(c)"[Coalescence] will be in response to repressive and provocative acts on the parts of...institutions of the 'establishment'; it may also occur as the result of disappointment from perceived failures of [social institutions] to take ameliorative action after raising general ...expectations that such would be forthcoming" (Mauss 1975, 62).

(d)Ashton elaborated on this point in the interview: "If the patients did try and complain about the side effects of medication, the staff would write that down as "agitation". If they complained about hearing voices or they hallucinated and they were so frightened that they couldn't even sleep in their own beds, then the staff would throw them into seclusion. All we did was keep telling this individual to tell your doctor, tell your doctor. And the only way that this individual could get his attention was by writing a note to him everyday, making a statement that she would sue the doctor if the doctor did not reduce the medication because of the side effects. It was terrible. Her tremors were just really terrible.

"When she did that [wrote the note], they called it agitation. We agitated her....But how can one say 'Hey! I'm hurting from the meds!' if they're not going to listen or give her more meds just to quiet her up. And that's just what they did" (Ashton interview, 1983).

(e)Psychologistic explanations may used against any group whose politics are at odds with dominant social institutions. Phil Brown (1985, 60-1) notes their use in the 1960s applied to black liberation, antiwar and student movements.

In this regard, Bruno Bettelheim's comments before a Congressional subcommittee are especially revealing. Speaking as a psychologist, he did not believe student activism was political in nature. "The symbolic meaning should not be overlooked of students' invading the dean's or president's office, violently, or by means of sit-ins, big in age and size, who inwardly feel like little boys, and hence need to play big by sitting in papa's big chair." He adds that the students hated their parents and themselves, so the students would not really "sit" in the surrogate father's chair. They were attacking the university as a surrogate for attacking their fathers..."It was unnecessary to treat protest as a political event. It was instead, a manifestation of psychopathological behavior" (Brown 1985, 60-1).

(It is not clear whether Bettelheim aims these comments only to men involved in student activism movements; if he was unaware of vast numbers of women participating; or simply reflecting the normative sexism of his discipline.)

A similar psychologistic explanation offered a psychiatric "solution" for the Detroit race riots of 1967. "Vernon Mark and Frank Ervin suggested that individuals' innate violence ('episodic discontrol syndrome') caused the riots, and that preventive psychosurgery [e.g., lobotomy] could prevent further outbreaks" (Brown 1985, 61).

I concur with Ashton's belief, however, that expatients many be the most vulnerable to these types of "explanations" for political behavior.

(f)Even a grudging acceptance of the work of mental health consumers is often cloaked in demeaning, patronizing language. A Detroit News article (9/6/82:18A) reviewing consumers' efforts to reform the Michigan system illustrates dynamics Ashton identifies here: "Sometimes you get tired of their yelling and posturing," admitted a mental health official, "but beyond that, a lot of things they're saying need to be said. They just want us to make a quantum leap forward. We can't do that."

(g)OASIS Fellowship is an advocacy group whose members are predominantly parents of mental health consumers, although some retired professionals are also included.

(h)The Manic-Depression Association is a support group whose members are people labeled with this diagnosis. They meet each week and have been in existence for several years. Plans are pending for the group to incorporate as a non-profit business.

(i)The Assertive Community Treatment (ACT) program is an innovative development in Lansing. It is a model program also used in other Michigan cities. The program sends counselors to community sites to meet clients, rather than having individuals come to an office setting. The program was developed to meet the needs of people deemed "chronic mentally ill," who cannot or will not use traditional services of a Community Mental Health agency, such as Community Support Services, where most therapy sessions occur.

(j)The City Rescue Mission provides meals and overnight shelter to indigent people in the city. It mandates attendance at a religious talk before services are rendered.

(k)The Salvation Army provides emergency shelter for people in need and assists with other living essentials as well (i.e., food, clothing, furniture).

(l)Adult Foster Care (AFC) residences are private homes operated by non-professionals who obtain funds from the state for upkeep of identified individuals. AFC homes provide services to many special populations, people labeled "mentally ill" among them.

(m)Group homes are licensed facilities, monitored by the state to provide living arrangements for special populations. Although group homes for adults with mental retardation characteristics outnumber homes for people labeled "mentally ill," there are several of these latter homes in the greater Lansing area.

(n)The "Jefferson Award" was granted on the basis of "outstanding community service work" (Staff Writer. "Jefferson Awards Go to Five," Lansing State Journal, April, 1982) and presented in person by Mayor McKane of Lansing.

(o)In the program prepared for the presentation banquet, the Tri-County Distinguished Volunteer award committee described the basis for the honor:

[Steven Ashton] has founded and guided one of the most effective self-help organizations in the nation, [Alternatives By Consumers], which provides a network of support to scores of individuals in the Lansing area. He has also inspired the development of other such groups in Michigan and has represented the self-help movement at meetings in Washington, D.C. [Steven] spends 12-16 hours daily working with people with emotional or mental problems....[Steven] also serves as a resource to mental health professionals throughout the state ("Tri-County Volunteer Awards," biographical sketches prepared for distribution at the public ceremony, 1982, p.1).

(p)Kathy Ferguson (1984) seems to capture the negative dynamics of bureaucracy that Ashton responds to when she connects membership in a bureaucratic society to a political situation "subject to a set of forces and pressures through which subordination is created and maintained" (Ferguson 1984, 83). Although Ferguson's thesis depends on parallels between the traditional roles for women and membership in a bureaucratic society, the felt constraint of the bureaucracy itself, as it maintains and creates subordination to "policy" or "program" clearly echoes Ashton's fault-finding with bureaucratically structured consumer programs.

(q)While use of a video for presentations is not unique to ABC (two other consumer groups at the DMH conference also used videos as part of their presentation), the manner in which it developed and the sophistication it embodied provide example for other consumers. Ashton and I were both involved in writing the script and planning the sequence of camera shots for it. We were also privy to much good advice from other ABC staff and volunteers. The video production crew we hired provided expert advice, camera work and editing help, but the video was consumer-inspired and consumer-produced. Other consumer groups with videos allowed the professionals to direct the project. Ashton and ABC demonstrated again that "consumers can do for themselves."

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MENTAL HEALTH CONSUMERISM REVEALED:
TOWARD A THEORY OF SOCIAL VULNERABILITY STATES
Volume II

By

Marion L. McCoy

A DISSERTATION

Submitted to
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Chapter 6

Chapter 7

Chapter 8

PART III

Individual Data Analyses

Chapter 6 - Consumers' Treatment Experiences

Chapter 7 - Experiences at Alternatives By Consumers

Chapter 8 - Consumers' Suggestions for Change

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CHAPTER 6

CONSUMERS' TREATMENT EXPERIENCES

Introduction

An earlier literature review (Chapter 2) reveals that mental health consumers are among the most discredited people with regard to research in the field of mental health. They are the least listened to and the most discounted when consulted. "Bracketing this natural attitude," we turn now to hear the perspective consumers bring to their own treatment experiences.

A centerpiece of this chapter is the notion that personal histories may be seen as "treatment outcomes." This broadens the usual scope of treatment outcome, commonly referenced in the field of medicine only to specific, measurable effects of a prescribed intervention (treatment). This common notion is inadequate to describe the social processes known to affect "mental patient careers,"[1] which extend far beyond administration of treatment. In the interplay between individual treat-

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[1] Erving Goffman is credited with illuminating the concept of career trajectories for people receiving inpatient mental health care in "The Moral Career of the Mental Patient," *Psychiatry* 22 (May 1959): 123-42.

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ment regimes and the social milieu created by consumers' shared travel through experiences in the public mental health system, treatment outcome is shaped in specific fashion.

For some consumers, the definition of their situation as "mental patient" in a system where they have no power becomes entrenched by their experiences. Professionals and peers within their social realm maintain this social construction. Neither do treatment regimes provide them with empowerment which could alter their definition of self as "mental patient." Thus, they continue to be a "mental patient," accorded by self and other-definition.

However, there are some consumers whose definition of self as powerless "mental patient" also begins in the public care system for whom the impact of peer behaviors and sentiments (and less frequently, of professionals who "violate" rules of professionalism) imparts empowering knowledge. This new knowledge allows them to alter the received definition of the situation, and the opportunity to construct an identity no longer dependent on their "mental patient" status.

These dynamics, which impel consumers to maintain or alter their socially constructed identity as "mental patient" are revealed in the data which follow.

Treatment Experiences, Sample Participants

For purposes of this discussion, treatment experiences refer to interventions prescribed by professionals and/or providers as a means to accomplish a tacit objective, the achievement of mental health for the person involved. Treat-experiences e

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ment experiences encompass inpatient and outpatient care received from the mental health system. Thus, treatment may involve psychotherapy, inpatient care (by voluntary admission or commitment), administration of psychiatric medications, electroconvulsive therapy (ECT), sterilization surgery, group psychotherapy on hospital units, participation in inpatient hospital programs, and participation in outpatient rehabilitation programs (e.g., vocational rehabilitation work training programs). The treatments examined in this chapter are limited to: psychiatric medication use; individual psychotherapy; use of "Emergency Services" and "Night Care" mental health care agencies; psychiatric inpatient experiences, including psychotherapy offered during hospitalization; and electroconvulsive therapy (ECT).

Inpatient and Outpatient Psychiatric Medications

Many consumers' psychiatric history is dominated by their experience with "major psychiatric drugs"[1] which can be categorized into three groupings: major tranquilizers (also called antipsychotics, ataraxics, or neuroleptics); major antidepressants; and lithium (Breggin 1983, 4). Consumers in this sample have also received drugs described to them as antianxiety medications, which are minor tranquilizers (Breggin 1983, 5), but usually for brief periods or only on an as-needed basis.

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1. These are identified by Peter Breggin (1983, 4) as "those pharmacologic agents used to treat the more serious problems seen by psychiatrists, such as schizophrenia, severe depression..." [and manic-depression]."

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Mental health consumers draw on their "received knowledge" (usually from psychiatrists) to understand the alleged need for medications to treat "mental illness," or as treatment for specific diagnoses which represent "severe" or "chronic" "mental illness." The most ardent supporters of medications treatment in this research sample were people diagnosed as "manic-depressive," all of whom were receiving the metal lithium,[1] "used in its salt form as a therapy for mania and sometimes for depression, as well as for the long-term prevention of extreme mood swings" (Breggin 1983, 4). Other consumers, whose experience was with "antipsychotic" (major tranquilizers e.g., Thorazine,[2] Navane, Mellaril, Prolixin, Stelazine, Haldol, Serentil) medication, are less convinced of the drugs efficacy or their need for it and complain of a host of unpleasant side effects (e.g., vomiting, dizziness, muscle spasms or stiffness, blurred vision, dry mouth, constipation, frequent urination, depressed appetite and sexual drive, weight gain, headaches, slowness of thought, inability to concentrate, edema, restlessness, lethargy). A few consumers found benefit from drugs described to them as "antianxiety" agents (e.g., Xanax, Librax, Librium), but were rarely prescribed these on a long-term basis. Others credit

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[1] Some consumers labeled "manic-depressive" were prescribed a time-released form of lithium called "Lithibid." Lithibid apparently assuages some of the gastric distress frequently caused by administration of lithium.

[2] These are brand names. Consumers routinely use only brand names in descriptions of their medications. I list them here because they frequently appear in interview excerpts.

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"antidepressant" (e.g., Deseryl, MAO inhibitors,[1] Tofranil) drugs as helpful to them.

Research which demonstrates the actual effects of all drugs mentioned above, but especially the major psychiatric drugs, has been ignored, suppressed, altered and/or denied by most practitioners and the official bodies which represent their interests (e.g., American Psychiatric Association; American Medical Association; National Institute of Mental Health).[2] Before proceeding with this discussion, a summary finding of such research should be noted:

> All the major psychiatric drugs are highly neurotoxic (poisonous to nerve cells); all frequently produce widespread brain dysfunction in their routine therapeutic dose range; and all achieve their primary, overriding effect on the patient by producing some degree of brain dysfunction (Breggin 1983, 4).

The information on these drugs, noted above by Peter Breggin, was not supplied to one consumer in the sample to whom they were administered. This finding is hardly surprising. Most of the mental health professionals (and significant numbers of non-psychiatrists) who prescribe these drugs rely on the educational materials provided by the drug manufacturer and/or on research reported to the official medical groups and their journals for information about drugs they wish to pre-

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1."MAO (Monoamine oxidase) inhibitors," are powerful antidepressants. Unlike other major antidepressants, MAO inhibitors require careful attention to diet, as some foods interact with the drugs, and may result in Central Nervous System distress (e.g., convulsions) or death.

2.For details, see especially Breggin (1983); Hill (1983); and Magaro et al. (1978).

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scribe. It is noteworthy that a majority of funding used by these official groups and journals is supplied by the drug manufacturing companies (Breggin 1987). Additionally, Phil Brown has noted that:

> The indiscriminate use of psychotropic drugs, with hardly any concern for their utility and/or effects, is one of the chief outgrowths of post World War II mental health policy. Deinstitutionalization has proceeded on the technical basis of psychoactive drugs, which mask or decrease many symptoms. While early deinstitutionalization preceded widespread introduction of psychoactive drugs, without those drugs state authorities would never have entertained discharging tens of thousands of back-ward patients... Community Mental Health Centers, designed as an alternative type of facility, have used drugs widely... (Brown 1985, 158).

Some consumers observed at Alternatives By Consumers (but not interviewed) express an understanding of the irreversible neurological damage, tardive dyskinesia, that occurs with psychotropic drug use. Many consumers exhibit signs that tardive dyskinesia has already occurred (e.g., through involuntary lip smacking or tongue movements, shuffled walking gait, hand and leg tremors, difficulty with pronunciation of certain hard consonant sounds), but because the drugs mask these symptoms, many will not know how severe the damage is until/unless they discontinue major tranquilizer drug use. Most consumers who manifest these signs are entirely unaware of them or if aware, do not know their cause (including two people who are in the research sample).

Sample participants' psychiatric drug history and current use appear in Table 11 (below). Only two people in the sample have no history of psychiatric drug use.

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Table 11: Psychiatric Drug History and Current Use, by Gender

Psychiatric Medication Types (N=13)	Women (N=9) Current	Past	Men (N=4) Current	Past	Totals Current	Past
Major tranquilizer	3	8	1	4	4	12
Minor tranquilizer	0	2	0	1	0	3
Major antideppresant	0	1	0	2	0	3
Lithium	2	4	1	2	3	6
Total types:using/used	5	15	2	9	7	24

Within this medicated cohort, 92.3% have received major tranquilizers; 66.6% have received a series of major tranquilizers; and 62.5% have received a series of major tranquilizers and lithium.[1] The mean number of major tranquilizers used for each person prescribed them at all was 2.58; the mean number of minor tranquilizers for each person prescribed them was 1.3; and the mean number of major antidepressants used for each person prescribed them was 1.25. All persons for whom lithium was prescribed were formerly or are currently also prescribed an adjunct major tranquilizer. More than half of the people once prescribed these medications no longer use them (i.e., 53.8% or 7 of the 13 people with drug use history).

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[1] All people currently taking lithium are diagnosed as "manic-depressive" (i.e., a bipolar major affective disorder). Currently, it is practitioners' "treatment of choice" for the diagnosis.

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Some people regard these medications as a positive treatment, but this sentiment is usually qualified by noting unpleasant side effects. Alice Wetherby was "slowed down some" by prescription of major tranquilizers for anxiety, which she describes below.

> You have anxiety ... so bad, that ... you just want to crawl out of your own skin. ...You can't sit still, you can't think ... you can't get involved [in anything] ... sleep is impossible, and ... you're going left and right ... in a circle. ... I've been asked to ... try and ... pinpoint something, anything, out of there, and I couldn't. I couldn't ... concentrate long enough to [do it]. ... They put me on Mellaril and Thorazine [major tranquilizers], and they did slow me down some (Alice Wetherby 1987).

Although Alice credits the tranquilizers as helping her "slow down," she also knew that: "If you think about it, that don't deal with what's going on and causing the anxiety" (Alice Wetherby 1987). She also qualifies the benefits the major tranquilizers provided by noting the "problems" their use caused her:

> They caused problems, too ... The Thorazine was drying my nose out so bad I was having nose bleeds left and right. I went to the doctor and she told me to put Vaseline up my nose. I told her I'm not taking this, so she switched me over to the Mellaril. I didn't like that; it was still causing me problems with drying me out so bad....[and I gained weight while using them, too] (Alice Wetherby 1987).

When Alice told her doctor she didn't want to take the medications any longer, the doctor's comments imply that without medications, Alice should expect to be readmitted to the hospital and remain in a continuous state of anxiety. Alice relates this exchange below, and reflects back on her early, difficult experiences without taking the medications.

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> doctor] told me: what are you gonna do? come back and forth ... ? Are you gonna end up in the hospital? Are you gonna end up in Night Care? Are you going to keep calling ES [emergency services]? I said: if I need to, but I feel it'd be better if I was off them. And maybe it'll be rough at first. ... I'm keeping that it mind, that it's not going to be easy, and it wasn't. There was a lot of anxiety, a lot of sleepless nights (Alice Wetherby 1987).

Alice's insight into use of psychiatric medications, i.e., they mask problems that need to be examined, and her painful but successful efforts to take herself off them are laudable. Not all consumers would challenge such a strong social construction of continuing "illness" that was presented to Alice by her doctor.

A similar example, without warning of dire consequences, is supplied by Martha Wright in the following excerpt. Part of her belief about need for medications may stem from what she was told by a hospital therapist about "managing her manic-depression."

> [I was told by a therapist on the psychiatric hospital unit that] You might always be manic-depressive, and you might always need to take lithium, and you might need to even take an antipsychotic [major tranquilizer]. But you can learn to manage the illness (Martha Wright 1988).

Martha Wright can demarcate her mental health system experiences with drugs by the diagnosis she had at different stages in her career. Prescriptions of major tranquilizers coincided with her first diagnosis, schizophrenia.

> When I was on Navane [a major tranquilizer] my diagnosis was still schizophrenia. ... Nobody ever questioned the diagnosis. ...One doctor would give me Thorazine [a major tranquilizer], the next one would give me Stelazine [a major tranquilizer], the next one would give me Navane ... They would change the medication, but the diagnosis always stayed the same (Martha Wright 1987).

When Martha's diagnosis changed, so did her drug prescrip-

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tion. As a diagnosed "manic-depressive," she was started on treatment with lithium. It is clear that there is tension in the beliefs expressed by Martha about lithium and the major tranquilizers. Below, she says that she "gets sick" when she forgets to take lithium. At another point, she says that she "gets sick" even when she takes lithium regularly.

> [When] he changed my diagnosis to manic-depressive, ... he put me on lithium. ... (sigh) I still get sick. ... I think the problem is ... that I start to get manic and I forget to take my pills and it just gets worse and worse and worse (Martha Wright 1988).

Above, Martha unwittingly communicates that the drug does not prevent mania (although lithium is alleged to be an "antimanic" drug).[1] It isn't until she "starts to get manic" that she forgets to take her pills; it is when she is taking them, ergo, that the "mania" first begins. She supports this construction later in the interview as well. Below, she describes being on lithium, which she was taking regularly, but it did not prove "helpful" as a means to avoid psychiatric hospitalization.

> I feel good on lithium. ... [But] I don't know if it's that helpful...I'm not sure, because I got hospitalized...being on, just my lithium. ... And they kept me on ... the same amount. They didn't change it at all. They just put me on Prolixin [a major tranquilizer], too ...and I got sick again and went home. Came back, got

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[1] "There is a lack of evidence for the major theories of the biochemical origin of mania and depression. In addition, the supposed specificity of lithium for mania is used to justify biological theories of mania. ... (T)his alleged specificity [is] challenged by extensive clinical data indicating that lithium has a general subduing effect on animals, newborn infants, and many other individuals who cannot be considered "manic" or "depressive" (Breggin 1983, p. 192). For discussion of this clinical data, see Breggin 1983, pp. 192-224.

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> sick again, and ... so I was hospitalized off and on all [that] year...(Martha Wright 1988).

Below, Martha relates that the impetus for interrupting use of medications is their negative effect. Without them, she achieves her highest levels of productivity.

> Q: So, ever since the first hospitalization, you've been on meds?[1]
> R: Oh no. I would quit taking them. I would be so drugged up, I couldn't talk...And I hated that feeling, so come spring I would ... throw it away and I would go out and get a different job ...
> Q: How did you do without it?
> R: Good. Good. Good. Yeah. *My most productive periods were when I was not on medication*...then I would get sick again and then ... they would put me back on some different kind of meds (Martha Wright 1988).

In the next passage, it seems that Martha has adapted to her medications, and is okay with taking lithium and the major tranquilizer, Navane. With her changed diagnosis, she is prescribed less drugs.

> I hate being over-medicated...[I was] ... a lot under the ... label of schizophrenia. Now with lithium, ... I'm pretty normal. I can talk and stuff. And people maybe don't notice it. Except that I'm on Navane now too (Martha Wright 1988).

It is not uncommon for consumers to "learn" they must take them for life through experimentation without them. This process is sometimes long and arduous. In the following passages, Sarah describes what she experienced when she was committed to a public psychiatric hospital ward. Drugs are a large part of that experience. She has learned through trial and error what medications she believes she needs.

> Q: Have you been on any psych meds, besides lithium?

1."Meds" is mental health consumer vernacular for psychiatric medications.

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> R: Oh, I can't, I've had so many. Haldol, Navane [major tranquilizers], Xanax [mild tranquilizer], antidepressants ... But see, ... when you're committed [to the public mental health floor], they put you on these meds and then it makes you ... Is it Haldol [a major tranquilizer], the one that you need Cogentin[1] [for], that makes you walk like a zombie? (singing) Walk like an Egyptian. Then, ... they'll take you off that, then they'll put you on something else, and ... you're not cleared. Your mind isn't clear even to remember what you're taking ... No, I've been on everything (Sarah James 1987).

Sarah also recounts the physical problems that have arisen as she continues to take lithium, a medication she believes she will have to take the rest of her life. She also describes the medication she currently takes as a "mild tranquilizer," which may have been how it was described to her. Serentil is a major tranquilizer.

> R: Right now ... I take Serentil ... a mild tranquilizer, ... but that's only as necessary.
> Q: Are you still on lithium?
> R: Oh yeah. Will be for the rest of my life. Messing up my liver, messing up my thyroid. My stomach. But yeah, I'll be on it. Messing up my skin.
> Q: You said you'll always take lithium. Did somebody tell you that?
> R: Well, no. I will take it. I learned the hard way ...I pretended... for about a year and a half... I got the lithium filled, made everybody happy, ... came home, soon as I was alone ... I flushed the lithium down the toilet. I am not sick, I don't want to be sick ... I wouldn't have any part of it, I wouldn't take it ...[but after another] humiliating hospitalization, [I learned.] No, I will stay on it now ... (Sarah James 1987).

Sarah's belief in her need for lithium was constructed by her experiences without it (which required readmission to the hospital); by professionals prescribing it to her; and also by peers similarly diagnosed as "manic-depressive." (Sarah regularly attended a "manic-depressive" support group held one

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1."Cogentin" is a medication given to counteract the side effects of some psychiatric medications.

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night per week at the Alternatives By Consumers building. At a different point in the interview, she told me it was through contact with members of that group that she "learned to accept that [manic-depression] is a life-long illness," requiring "maintenance care" on lithium.) It appears that Sarah's allegiance to this constructed belief about lithium (and by extension, her "illness"), outweighs her concern over physical problems caused by continued use of it. If taking lithium keeps her out of the hospital, she must need to keep taking it, in spite of the problems it causes.

Sometimes, the effects of the medications were more than physically unpleasant. Below, Karen recounts various consequences of psychiatric drug use. Without health insurance coverage, there was financial strain involved in weekly blood tests to monitor concentrations of lithium[1]; severe edema requiring purchase of different clothing; and experience of general lethargy. She mentions the relief felt when she quit taking the medications altogether. The number of medications prescribed for her is common.

> R: ...I was on lithium when I got out the hospital. I stopped taking that. For one thing, my insurance had run out. And I was gonna have to pay for these blood tests and I said: Forget that, I don't need that medication anyhow. Then I was on Navane [a major tranquilizer], and I stopped taking that. ... I didn't feel right on that. Then I was on Mellaril [a major tranquilizer], that [made me blow up overnight]... I mean, can you imagine me with big fat jaws, they're like that [she holds her hands out, several inches from her jaw line]?

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[1] Beyond a certain concentration in the bloodstream, lithium becomes toxic, causing severe diarrhea, vomiting, convulsions and/or death.

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> Q: What? You had a lot of fluid retention?
> R: Yes, from the waist up. And so I stopped taking it. ... Because my clothes, well...[I had to buy clothes that were 3 sizes larger than my old ones]. So..[I quit them]. And I told Steven [Ashton]: I really felt better [off them] because seemed like I could comprehend ... I could think. I didn't feel so druggish ... when I was on the medication, I always felt real sleepy. He said: I know what you mean, Karen... (Karen York 1987).

Karen was "helped," by financial strain and physical problems, to alter her received construction about the need for psychiatric medications. When she finds she can "think again" after she discontinues their use, the definition of the situation that mandated their use "for her own good" is changed.

It is significant that Steven Ashton, a consumer peer, supports Karen's decision. (His support was more extensive than discerned in this excerpt. Karen communicated that Steven supported whatever treatment decisions she made when they appeared to her as "the right thing to do" during the course of her interview.) Peer support for changing the definition of the situation in Karen's instance contrasts with Sarah's experience (above). When Sarah's peers encourage her to continue lithium for life, side effects that disturb her do not result in the drugs' discontinuance. These findings echo a theme of inpatient experiences (reviewed below): alteration or maintenance of a received definition of the situation are significantly impacted by communications from consumer peers.

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therapy is helpful, possibly essential, to their eventual recovery. Their perseverance in seeking psychotherapists is revealed by summary statistics: 5.86 is the mean number of therapists consulted; 10.2 years is the mean duration of time spent in any kind of psychotherapy; and 3.6 years is the mean duration for work with one therapist consistently.[1]

Most consumers in the sample have had a number of different therapists. Therapist turn-over in the public system is one aspect relevant to this finding. Pamela reflects on the series of therapists she has had in the following interview excerpt:

> I've had so many different therapists, that I'm about ready to give up again. ...I went to Ingham [Medical Center clinic], I went to St. Lawrence [Hospital outpatient clinic], [and] I finally went to CSS [Community Support Systems outpatient clininc]. [When my case manager left] CSS... I went over to [a private clinic that'd take Medicaid]...but when [CSS] found out that ... they went to cut off. Just like that. [Now I'm working with another CSS therapist again] (Pamela Martin 1987).

Pamela left the Ingham Medical Center clinic because they could not accept Medicaid, the benefit available to public mental health consumers that covers psychotherapy. When she transferred to St. Lawrence outpatient clinic, the therapist she was seeing there left to accept private sector employment. When she returns to CSS (the Community Mental Health Center agency that serves outpatients), the case manager/therapist she is assigned leaves before a year has elapsed. She was

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[1] This latter figure is inflated for this small sample by two people who have worked for many years with the same person. It is not a "typical" finding for public mental health consumers as a whole.

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pleased with the therapist she locates privately, but CSS intervenes, and she is assigned to another CSS therapist instead. At the time of the interview, she was trying to negotiate continuance of therapy at the private source with CSS approval. This series of changes proves stressful for Pamela, and "makes her want to give up again." The bureaucratic structure of the public system cannot recognize possible untoward effects of frequent change in therapists, providing no incentive for therapist or patient to continue working together.

In the passage below, Sarah loses a therapist assigned to her after her first hospitalization. She tells me she was bereft when the therapist left CSS.

> I just started to trust Julia, then Julia left ... Julia ... is superb ... And when she told me ... I felt like I was being betrayed. Fine. I open up and talk to you [and then you leave and go back to school] ... You know, with Sue [the therapist I got after Julia], there's no way that she would ever add up to Julia (Sarah James 1987).

Sarah is distressed when her therapist leaves the public system. Sarah experiences the leave-taking as "betrayal," having mastered her own trust issues sufficiently to confide in the therapist. On the other hand, high case loads and public sector pay rates may explain why this therapist, and many others, feel they have little choice about leaving the system if they are interested in career advancement. The stress of this quandary may be unequally borne, however: public mental health consumers have no options for private payment toward psychotherapy costs if they leave the system.

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A related finding from this research is that if employment-related health insurance coverage is terminated when consumers become hospitalized, the realm of therapists willing to accept Medicaid benefits limits access to psychotherapy for consumers. Below, Sarah attempts to return to a therapist she saw for three years before entering the public mental health system, after her abrupt termination with her former CSS therapist (Julia).

> I have to say [I worked better with] Julia, even more so than Elsie [although I worked with Elsie 3 years]. Now I can't even go back to Elsie because I'm on Medicaid, they don't accept Medicaid. Isn't that nice? ... I tried ... over a year ago, when Julia left. I said: hey, as long as I gotta start over with a different therapist, I may as well go back to Elsie. Wrong ... So it's like, here you are. So, frustration, really (Sarah James 1987).

Sarah finds she cannot return to the therapist she wanted to because her benefits would not cover the session. The bureaucracy of the system cannot permit the return. There is no provision in the rule-bound structure that could help Sarah reconnect with a trusted therapist, nor recognize the difference it might make to Sarah's eventual recovery.

But it isn't only the public mental health system with high turn-over rates that interrupts ongoing therapy. Many private sector psychiatrists and psychologists chose not to work with people who have a "chronic mental illness," and/or a diagnosis which carries probabilities of long-term therapy (e.g., borderline personality disorder, manic-depression, schizophrenia).

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state hospitals. A preponderance of foreign-born psychiatrists are employed at state institutions, where regulations governing medical practice are less stringent than those governing private licensing. This makes it less likely that foreign-born psychiatrists will have private practice in local communities. Thus, psychiatrists at these institutions have less choice of clientele. Local psychiatrists have greater choice and hence, can turn away the more "disabled" consumers. When local care is disrupted by a series of practitioners and recovery thwarted for the involved consumer, their condition may worsen to the point where it draws attention from others. When observers seek to intervene and notify authorities, the consumer is often refused local inpatient care and sent to a state facility. It is this circular pattern that contributes to popular beliefs: severely disabled people are found in state institutions and certain diagnoses are more disabling than others (i.e., ones that require long-term psychotherapy). It is noteworthy that this myth might be easily disarmed were this circular pattern halted.

In the passage below, Jeff summarizes the rejection he experienced from private <u>and</u> public sector mental health professionals.

> R: ... I got dumped by about six private shrinks and, CMH [Community Support Systems, CSS] won't see me because I was their problem child. I terminated my services over there after they treated me like a dog and kicked me in the face [when I participated in their employment training program], and all this good shit.
> Q: So all together, how many therapists do you think you've seen?
> R: I've seen 27, at the Veterans Administration ... and out here in Lansing, and a couple in [a large city I lived in]...(Jeff Bell 1987).

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Jeff's tenacity in seeking a psychotherapist who "has compassion and competence" (Jeff Bell 1987) speaks to a strong belief in psychotherapy as a needed element for his recovery. It is noteworthy that his altercation with system providers in the employment training program results in "closing his case" with respect to psychotherapy options as well. The structure of the system prevents attention to selected areas within the realm of mental health care. It appears that public consumer care is sometimes an "all or nothing" proposition.

All sample participants credit psychotherapy with "helping" them cope with their problems to various degrees. One exception to this general trend is noteworthy, however. Carly Willis was court-ordered to engage in psychotherapy with a public mental health system therapist for 90 days following commitment to inpatient care. Like others in public mental health, her therapist was at CSS (Community Support Systems). In the passage below, Carly relates an incident with this CSS therapist that may explain why she subsequently left the public system to seek private sector psychotherapy.

> R: They told me that if I didn't go [to the court-ordered CSS therapist], that they could put me back in the hospital, so I went. Half the time, I'd show up a half hour late. Other times I showed up drunk. One day I can recall showing up with a vial of drugs and showing it to the therapist and telling her I was gonna kill myself.
> Q: And what'd she do?
> R: Nothing. That's about what it was.
> Q: Well, what happened?
> R: I overdosed that day (Carly Willis 1987).

It appears that the psychotherapeutic care offered by this public system therapist did not offer Carly enough support at a time when she was vulnerable to suicidal impulses.

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Since most psychotherapists are taught to regard suicidal ruminations (let alone evidence of suicidal intent) as indicators of a need for intervention, the exchange Carly relates here suggests that court-ordered psychotherapy may adversely affect both parties. Carly reports behaviors that suggest resentment with the arrangement and the therapist manifests behaviors that suggest inattention to crucial (perhaps life-threatening) issues in Carly's life.

Even when psychotherapy is voluntary, other structures of the bureaucratic system impinge on consumers' experiences with this treatment. For consumers in the public mental health system, whose psychotherapy is usually limited (by high therapist case loads) to one hour per week, a time of great travail is when they cannot reach their therapist and need to do so. In the passage below, Martha describes what happened to her when she was not allowed to consult with her Community Support Systems (CSS) therapist/psychiatrist during a crisis.

> I went to [CSS] and I said: hey, I'm getting sick. I haven't slept for a couple days and I really need to see my psychiatrist. And they refused to let me see him. He would not see me. He says: I don't have to come in just because you ... And he refused to see me, so I had nothing else to do. Well, I went home and just got sicker and sicker (Martha Wright 1988).

The events Martha describes ended with an admission to the psychiatric unit of a local hospital. It is plausible that this admission might have been avoided had she had access to her psychiatrist. His refusal to see her left her with "nothing to do (but) get sicker and sicker."

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contact their therapist after business hours. Ben Harris, heard in the following passage, was the one member of the sample with a public mental health therapist who had been given his therapist's home phone number.

> Q: ... what if you felt like you really needed to talk to [your therapist]. Could you call her any time and reach her?
> R: Yes. She is available. She's given me her home phone number.
> Q: Does this help? Knowing that?
> R: Yes. Yes it does. Help in the sense that she really cares. Oh well, I put my 9 to 5 job in. Now, get lost. She cares. ... I find no fault or flaw in her as a human being, and she really cares. What I'm saying is from a technical standpoint, she may not be able [to do] that much (Ben Harris 1988).

Although Ben has expressed doubt about her "technical" competence, giving Ben her home phone number communicates that she cares about him, which he emphasizes above by repeating the phrase "she cares" three times in three sentences.

Carly found a private therapist after her negative experiences with public therapists. She worked with the private therapist for four years before terminating the arrangement by mutual accord (about 2 weeks prior to the interview). Below she tells me what having her therapist's permission to call her "any time" means to her.

> I called that person at home sometimes and yeah, she told me that she wanted me to know that I could call her up at any time. ... It gave me a feeling of security ... And it just kind of gives you the motivation to go and try it, knowing that there's something to fall back on if [terminating therapy] doesn't work (Carly Willis 1988).

Knowing communication with her therapist is possible "any time" provides security for Carly's fledgling efforts to fly solo, without scheduled psychotherapy sessions. As we have een, this

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seen, this security is not routinely available in the public system.

What may be more contentious for public mental health consumers is being granted permission to contact a therapist after hours, then having that access rescinded. Dana Monroe reports that this happened to her in the following passage.

> Q: Can you call [your therapist] at any time and reach her?
> R: No. ... It's kinda hard because for a while she was letting me call her at home when issues came up. And then she decided that wasn't therapeutical so ...she stopped doing that.
> Q: So now it's nothing?
> R: Right.
> Q: What do you do when you feel like you have to call her and you can't reach her?
> R: Sometimes I call and hang up on her (laughing) (Dana Monroe 1987).

Above, Dana seems to make light of this refusal from her therapist to speak to her on an unscheduled basis, although calling and hanging up can be seen as a way of denying the "new" reality (i.e., 'I can too call you!'). In a different section of the interview, Dana reveals the importance of her therapist's support:

> Q: Who do you think of first, or call first, when you need help? ...
> R: Generally my therapist (Dana Monroe 1987).

Dana reveals that her therapist is a major source of support. She has also revealed that access to this major support is currently available only during week-day working hours. The situation socially constructed by these disparate messages from her therapist (i.e., "I will offer support after hours" and "I will not offer support after hours") is contingent on the authority of the therapist, and not on Dana's perception

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of need. If Dana defines her situation as one requiring her therapist's support, that support is contingent on the timing of Dana's need (is it during weekday working hours?) and whether the therapist currently believes that there is therapeutic value in after-hours contact. Thus, Dana's definition of the situation is discredited, subservient to the definition provided by her therapist.

Part of the reason that therapist support is so central relates to the shattering of social support networks that occurs upon entry into the public mental health system. Many people in this sample have been rejected by friends and families after they become consumers of mental health care. Comments which reflect this pattern among family members of people interviewed are diverse: "My mother disowned me;" "My aunt totally rejected me, wanted nothing to do with me so she had me committed to a state hospital;" "My brother thinks I'm just playing sick to get government disability benefits;" "My brothers and sisters think I'm off in my own little fog and don't call me anymore;" "I talk to my sister on the phone and she just keeps saying 'Now don't get upset dear, don't get upset.' I can't even have a real conversation with her anymore;" "My brother didn't want me near my own neices, he was afraid I'd hurt them without knowing it or something" (Interview numbers 1, 3, 4, 5, 10, 15, 1987-88).

If consumers do not or cannot turn to friends or family when access to their own therapist is denied, during a time of extreme anxiety or crisis the recourse to help allowed by the public system is contact with Emergency Services (ES).

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Emergency Services

Emergency Services (ES) is a Community Mental Health agency whose primary function is to handle day-time and after business hours crises for any person needing emergency mental health treatment. Although it predominantly serves established clients of the system, it is available to all area residents in need. There are two major divisions in Emergency Services, the on-site service and a phone-in service.

The on-site service provides a setting in which consumers can be evaluated for inpatient care needs, whether or not they are established clients of the care system. It is the sole entry point for people requiring inpatient public mental health care in the city, and is available on a 24-hour basis. In practice, it is sometimes difficult to find a psychiatrist and/or psychiatric intern who can be called upon to fill this intake position. (When Steven Ashton and I attended a meeting at the Community Mental Health Board executive offices during the fall of 1987, the Executive Director told us that intake psychiatrist positions at ES were difficult to fill and keep filled. Doctors routinely leave the public system for employment in the private sector.)

The 24-hour phone-in service provides callers with someone to talk to if they are "having problems," and/or a means by which consumers can request that their (CSS, public system) therapist return their call. In practice, consumers find that neither of these phone-in services function according to plan.

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Sarah describes her inability to reach her Community Support Systems (CSS) therapist during or after working hours using the Emergency Services link below:

> Q: If you feel you could benefit from talking to her, can you reach [your therapist at CSS]?
> R: I've tried. She's with a client, she's out to lunch, she's sick. They don't offer anybody else. (In a raised and somewhat agitated voice) See, that's the big thing, they don't offer any ...
> Q: Do you ever call after hours?
> R: Well, no. Because then you call emergency services.
> Q: How do you feel about that?
> R: (Sigh) I think it's false advertising, false pretenses! I really do. This is a therapist that supposedly knows you ... Well, what do you do for me when a ... crisis is arising? They don't offer anybody else to talk. Nothing ... And, of all places, mental health, they don't offer anything.... I think it's ironic. I think it's pathetic (Sarah James 1987).

Sarah describes the Emergency Services conduit to her therapist as ironically pathetic and fraudulent. The bureaucratic "fail-safe" feature has failed Sarah in her times of need. As a public system consumer, other system options for help are not available.

Sarah is not the only public mental health consumer who has experienced difficulties receiving help from Emergency Services. Alice has contacted ES many times through her years of public system experiences. In the passage below, Alice enlarges the perspective on the problem with Emergency Services:

> Q: If you wanted to talk to [your therapist after hours] and you call ES, could you reach her that night?
> R: It would have to be very important. I've never done that. Never had that go through ... there's supposed to be a statement from ES every time someone calls or comes in, given from ES to the therapist. ...I would always go in and say: Well, did you get a report [from ES]? And she'd say: no, what do you mean, a report?
> Q: Was there <u>ever</u> a time when you called ES and she got the message?

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> R: There's been times where ... I've acted out and she's gotten it. The next time I seen her she'd be knowing all about it. That's gone through, yes. But as far as me trying to reach her through ES,...that won't go through (Alice Wetherby 1987).

Alice's comments expose a possible bias at Emergency Services, i.e., ES workers will contact therapists if clients "act out" (e.g., give in to self-hurting impulses they are experiencing, which was the referent for Alice's use of the phrase above). They may be less likely, however, to relay calls for consumers who "only" need to talk with their therapist. In the absence of perceived support, consumers may experience difficulties that lead to psychiatric hospitalization.

Admission to the Hospital

When their mental health treatment experiences first begin, people in this sample report that they knew "something" was wrong, and are guided into a hospital if the practitioner they are consulting believes it is warranted. At the time of *voluntary* admission, the reliance on professionals to provide a "definition of the situation" is at a peak.[1] (Involuntary admission by commitment allow consumers no recourse to the definition of the situation provided by the Court ruling.) The following excerpt from Sarah's interview illustrates this dynamic:

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[1] This was first noted in Chapter 4: Steven Ashton's first voluntary admission to inpatient care was contingent on his acceptance of the psychologist's "definition of the situation."

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> That's when Elsie said: ... Sarah, you've got to do something. ... You've got to sort it out, you've got to find out what is ... So the very first time, I went in. I wanted help (Sarah James 1987).

Sarah acquiesced when the therapist she had worked with for three years suggested she seek inpatient care. Sarah tacitly agreed with the social construction of the hospital, and the nature of Sarah's problem, offered by her therapist, i.e., a hospital is a place to go to "sort it out," to "find out what it is," a place where you can "do something" about it. The "it" in these communications appears as something external to Sarah, and something to be treated by others (i.e., mental hospital personnel). Sarah's experiences in the hospital caused her to modify the social construction of a psychiatric hospital which she first agreed to, as well as the nature of her problem (as we see later in the chapter).

Typically, consumers in this sample admit themselves for inpatient care based on self-realized experiences or compulsions they have learned to recognize as indicative of a need for hospitalization (e.g., they are too depressed to get out of bed for days on end; they are overcome with anxiety; and/or they fear they will hurt themselves). When Sarah describes the condition for which she sought hospital admission, the language she uses belies a dependence on professionals' definition of her situation.

> I was ... having suicidal thoughts. I was depressed ... And I couldn't sleep because every time I closed my eyes, I would see a gun. I would see a knife. I never saw things...I never heard voices. ... But I couldn't sleep. It was like, I don't know what is happening ... And a fear that maybe my subconscious, or something would happen, and I would [commit suicide] ... And I didn't want to die (Sarah James 1987).

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When Sarah refers to a "fear" of her "subconscious," this implies that people knowledgeable about "subconscious" impulses (i.e., mental health care personnel) can help with her fear. She did voluntarily admit herself to the hospital at that time.

Alice also learned the "signs" that indicated she should admit herself to a hospital. In the interview, she credited the self-harming and suicidal impulses as the reason she signed in to the hospital during the time she describes below.

> Q: What was going on before you went into the hospital?
> R: I know there was stress about getting a job...I know I was getting very angry and very down on myself again, which I do quite easily, and then [I] feel very disgusted and not worthwhile. I want to hurt myself. Okay? Or [I] feel that I need to be punished...but I know I was going through a couple of things where ... I wanted to hurt myself and also ... I wanted to kill myself...that was very serious in my mind (Alice Wetherby 1987).

There is frequently a complex web of events and/or feelings that contribute to seeking inpatient care. Above, Alice has revealed that looking for a job; feeling angry; feeling disgusted and "down on herself;" not feeling worthwhile; and feeling a need to be punished all contributed to seeking hospital admission. Her knowledge of what "counts," however, in terms of why she believes she was admitted, was stated in terms acknowledged by the system, i.e. fearing she would harm herself or attempt suicide.

Refusal to Admit for Inpatient Care

Despite their recognition of need, several consumers in the sample have been denied admission to the hospital. Dana dicates belo

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indicates below that sometimes this is due to the intake psychiatrist's disagreement with the consumer over need for hospitalization. At other times, there is simply no room in the hospital.

> Q: Have you been refused admission to the hospital?
> R: Yes. ... Probably four or five [times].
> Q: What did they say ...?
> R: Basically, you see their doctor, and the doctor decides if you're having enough problems to go in, or if they think you can handle it on your own, or occasionally it's been they didn't have any open beds. So they tell you to go home. (laugh)
> Q: How many times was it because there were no beds?
> R: Twice at least (Dana Monroe 1987).

Another finding from this research is that these contingencies (i.e., the intake psychiatrist's definition of inpatient care need for the consumer, and availability of private versus public bed space) could be conflagrated for public mental health consumers. Hospital beds on the private floor might be available but the public consumer's need was not deemed serious "enough" to warrant use of a private bed. (Other times, private beds were made available for consumers of the public system.) Sometimes, consumers denied admission initially were notified of bed availability only after a bed on the public floor became open.

It is noteworthy that consumers in this sample who are refused admission had previous admissions to the same unit in the hospital. In the next passage, Bill reveals that when he left the hospital without permission during one hospitalization, they subsequently refused to admit him. Other people in the sample who had also walked out were <u>not</u> refused inpatient care later; this suggests a certain capriciousness in the ing levied ag

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> Q: Have you ever tried to get in the hospital and were refused?
> R: I tried, and I had a friend about two years ago try to get me back into St. Lawrence and [because] I'd walked out one time, they said I could never come back. Said they always had to refuse me (Bill Peters 1987).

Carly noted a problem with obtaining admission to inpatient care when she responded to the question, "Do you think there are factors that have affected your treatment, or the treatment of others, in the system?"

> R: ... Probably the people who have [been] chronically hospitalized, ... have a more difficult time getting into the hospital. ... I did see a girl that I was in the hospital with, a woman, who was basically told that they were tired of her, and that if she ever ended up there again, they were gonna send her to Ypsi [the state hospital in Ypsilanti]. She was [diagnosed as] a borderline and an alcoholic...
> Q: And she'd been in a lot?
> R: Yeah. Quite a bit. ... Yeah. You could see that with a couple of people that had been there over and over and over again (Carly Willis 1988).

Carly's comments reveal that people who are hospitalized on a repeating basis may have difficulty being hospitalized when they perceive the need for it. Alice illuminates this dynamic graphically, in the following passage:

> R: I had to ... argue, so to speak, with the doctors over at ES about getting back in because I needed to ...
> Q: What were they saying?
> R: Well, like ... you go in and say that you're feeling you're needing it and why, and then: "don't you think you could [handle] this at home?" Then you get upset and I'm trying to tell them: if I could I would. And they're not listening to what I am saying. ... They always think 'she just wants to be in the hospital.' This is not true. It's just that I know things are getting out of control, and please, I need some assistance. I've been trying everything ...I have a list in my mind of all the things to try, to keep trying and not stop, and they're not helping. ... It's almost like you have to fight with the psychiatrist to get in. First you have to go through the ES worker to get to the psychiatrist.

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> Q: You have to convince him or her that you need to see?
> R: The psychiatrist. Yes.
> Q: Then you have to convince him or her that...
> R: That you need to be in the hospital. Yes (Alice Wetherby 1987).

Several sample participants who were refused admission upon their request experienced an exacerbation of troubling conditions that led to their manifestation of certain behaviors for which admission could not be denied (e.g., self-harming and/or suicidal gestures or attempts), and so gained hospital admission in this manner (Interview numbers 1, 2, 3, 4, 5, 10, 11, 13, 15). Below, Jeff reflects on admission refusals and what followed in their wake.

> Q: Were you ever refused admission?
> R: Yeah. ... Numerous amount of times, but it all ended in a suicide, and I ended up there anyways (Jeff Bell 1987).

It is perhaps revealing that Jeff uses the phrase "ended in a suicide" instead of "suicide attempt." At first, I assumed that the substitution was unintentional: either I had failed to transcribe his quote verbatim or he hadn't noticed the omission as he spoke. Checking against the tape recording of the interview, I found the quote was accurate. I was surprised to hear this same construction in several other interview sessions (Interview numbers 5, 6, 9, 15). Like Jeff, these other people had predominantly negative hospitalization experiences. Although such small numbers do not allow conclusions to be drawn from this pattern, it may be that gaining admission to the hospital by attempting suicide is experienced as a "social suicide," ending all contact with the outside world to return to a place where these consumers know, experientially,

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Even when consumers succeed in being voluntarily admitted without further exacerbation of troubling conditions, they are sometimes summarily dismissed because the hospital needs the bed they are using for a new admission. Dana reports this below.

> A lot of times ... when I was in, I was released directly from the back side [the locked, intensive care area]. They had me on suicide precautions[1] one day, and the next day they're releasing me. ... If ... they're getting an admit, a new person coming in, and the unit's full, they'll discharge someone to make room for the person that's doing worse. So ... you could be discharged because they need the bed rather than because you're ready to go (Dana Monroe 1987).

To be accepted for care then rejected when still in need of it communicates a certain relativism in the nature of care accorded public system consumers. Their needs are important only until others' needs are discovered to be more important. In a public system overburdened by demand for services, the scenario described by Dana in the preceding passage is likely to be repeated many times.

Another route to hospital admission for consumers in this sample that depends on intervention of others is through the Night Care facility.

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[1] "Suicide precautions" require staff to observe patients every 15 minutes on a 24-hour basis and record their observations in patients' charts.

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The "Night Care" Facility and Admission to the Hospital

"Night Care" is a treatment program designed for use by mental health consumers requiring supervision at night, but who are deemed able to pursue independent activities during the day, on or off-site. It is conceptualized as a transition program, sometimes used to buffer the effects of discharge from the hospital or as a means to avoid total inpatient care by providing respite in the facility. Consumers in the sample report that in practice, it is also a screening center, which provides an opportunity for mental health workers to determine whether a need for total inpatient care exists, and authority to act on these determinations if warranted. (Eleven of the fourteen [78.5%] public mental health consumers in the sample have stayed at Night Care.)

Night Care also provides opportunity for professionals to "define the situation" for individual consumers who turn to them during times of great vulnerability. The interview excerpts in this section provide a forum for the tension between the situation as consumers define it for themselves and the situation as determined for them by mental health providers. The paradoxical operations of the bureaucratic system are noted as well, for it is also through the effects of the structural impingements on professionals and consumers that the definitions applicable to consumers are shaped.

In the passage below, Dana is reflecting on an experience when she was suspended from her group home. (She was suspended for breaking into an office to read her own records which were ept by the S

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kept by the supervisors on each resident.) She responded to the suspension by hurting herself, for which she was admitted to a local medical-psychiatric unit. She was admitted to Night Care from that unit. When Night Care staff find out she has obtained a lethal means to use for suicide, they commit her to the psychiatric ward in another local hospital.

> Q: What would you say caused them to commit you?
> R: I had tried to kill myself before that, and was in the hospital and had a couple of surgeries ... I injected two needle fulls of lighter fluid into my arm. And they had to lance it and drain it, twice, and then stitch it back together afterwards. And then ... they released me to Night Care. I was there probably about a week and a half, and I was having a lot of problems and didn't have anywhere to stay, so I got a hold of a gun, and they found out I had the gun, and committed me.
> Q: Do you know why you were going through all that?
> R: Pretty much rejection ... I was kicked out of the house the night I injected my arm ... [I had] No where to go. No where to go. I didn't feel like I had anybody to turn to 'cause most of my friends were at the house at that time (Dana Monroe 1987).

The system that provides Dana a residence in the group home is the same one that leaves her homeless and alone. The paradox is complete when the system operates to her benefit (committing her when suicide is imminent), but only after she has forced their hand by "dangerous to self" behaviors.[1]

Carly illuminates the "back-up" function that Night Care serves in the following comments. She tells me that after being refused admission to the hospital, she is offered a stay at Night Care as an alternative. When she is ready to leave Night Care, the staff "petition her in" (i.e., file commitment

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[1] Commitment by the court requires determinations that the person involved is "dangerous to self or others." (Michigan Mental Health Commitment Code, revised edition, 1982).

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> Q: Have you ever been refused admission to the hospital?
> R: Yeah, I remember I was suicidal and ... I wanted to go into the hospital. And they said I should go to Night Care. Then [when] ... I was ready to leave Night Care, they didn't think I was ready to leave, so they petitioned me into the hospital (Carly Willis 1987).

Carly's experience exemplifies the unwitting assumptions frequently made about "mental patients" by providers in the system. When she recognizes the need for hospitalization, the admission denial is predicated on an assumption that her own insight is not accurate. She is discredited. When she attempts to leave Night Care, her assessment of her own needs is again discredited, and she is instead committed to the hospital.

In the preceding incidents highlighted by Dana and Carly, Night Care staff intervened in situations deemed critical. Other consumers report that Night Care has failed to meet its purpose in this respect.

> R: Night Care should be shut down far as I'm concerned. ... They're a joke. They're hurting people. They're disappointing people. ... They were gonna kick me out ... whether I had a place to go to or not.
> Q: Any reason?
> R: I asked them. "This is a staff decision." You know? I have heard numerous cases ... of suicidal patients ... being thrown out of Night Care, into the streets ... and those people get out there and they kill themself. The staff at Night Care doesn't seem to know they're playing with people's lives. I told 'em the last time I was there ...'you know, you push people to the edge; you force them into crisis situations. It may be your mistake, but it may be that person's life.' Of all the systems, that one to me is the worst (Ben Harris 1988).

Ben is disappointed in Night Care, feeling that they did not help him when he was homeless and without options. His concern is also for others whose "disappointment" with the facility is fatal. To Ben, Night Care has failed to adequately fine the situ

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define the situation for consumers who leave the facility and subsequently commit suicide. He implies that failure to achieve a negotiated definition of the situation for consumers, where the needs of consumers are recognized and addressed by professionals in accord with individuals, is the feature that proves to be fatally disappointing for them. His comments are supported by the next voice heard.

In the following interview excerpt, Bill Peters summarizes the areas that Night Care ignores which he believes are vital to well-being for people in public mental health. It appears to Bill that at the time of discharge, Night Care staff disregard the plans they establish when people are admitted to the facility.

> Night Care. What I do not understand ... [is] they've got this plan when you're admitted. You've got to think of what you're gonna do while you're there. You've got to work your way off the problems here before you go over to there ... I would say about 75 to 80 percent [of the people] they cut loose at Night Care, number one, don't have no apartment. Two, don't have no money or anything. Three, don't have no place to go. Four, no job. Five, nothing they can really depend on (Bill Peters 1987).

Bill identifies lack of discharge planning as a problem endemic to Night Care, and one from which he suffered. He is perplexed because this seems to violate the logic of the program. Bill states succinctly what process is at work:

> I think with Night Care, communication is the biggest thing. Lack of communication [between] patients and staff (Bill Peters 1987).

This problem, lack of communication between patients and staff, pervades hospital experience as well. There are continuing tensions between definition of the situation offered by

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system operations (i.e., group home placement, group home denial, hospital commitment) by professionals in practice (e.g., 'we know when you need hospitalization, you don't'), and as perceived by consumers (e.g., 'I know when I need hospitalization, you don't').

Inpatient Behaviors

The recurring nature of specific kinds of problematic staff-inpatient relationships suggest a structural effect is impinging on these relations. When reliance on professionals is mandated, the elicited "second class" status from the subordinate/patient provides impetus for behaviors that will dramatically demonstrate how inept they believe hospital personnel on their wards are. When consumers have learned experientially that their words will be ignored and/or discredited, the remaining communicative medium open to them is behavior. Thus, consumers "act out" what language will not allow them to say. This proves to be an effective strategy within a mental health care bureaucracy that can only *react* to expressions of consumer need.

Through inpatient experiences, Sarah constructed a different understanding of the hospital and its programs than she once held when she first agreed to inpatient care. She willingly admits herself for care, then "begins to see it," i.e., the lack of attention to procurement of recovery skills during hospitalization. She has agreed to the definition of the situation first provided by professionals (hospitalization will aid your recovery) but her experiences teach her that their definitic

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their definition is inaccurate. Her anger and bitterness is apparent in the following excerpt.

> I did thoroughly admit myself. Then it got to be like a game. Then I tried the suicide. And then [I went] to Night Care. I was everywhere. ... And then I started seeing it. Oh, I mean, you tell me where this helps. Going to the park and throwing around a frisbee ... When I'm in your god damned hospital ... You suck the pride out of me. You suck out my self-esteem, self-confidence, self-worth (Sarah James 1987).

Sarah's experience of the care offered to her by professionals and the mental health bureaucratic structure via hospitalization is one that drains her of pride, self-worth and self-confidence. She learns to eschew the definition of her situation offered by the system. It is significant that an early response was constructed as game-playing: this is part of the process through which consumers learn that the game, played by rules of the superordinates, is harmful to self. The authorities demean and discredit and consumers acquiesce or "act out" in response. Because the care system is reactive, playing the game or violating rules of the game are the primary modes of communication between consumers and providers (unless or until another definition of the situation intervenes, as when consumers become involved in a consumer-run organization which affects definitions that consumers apply to themselves and their peers).

Other consumers learn to "play the game" as well, although some do not become embittered by this knowledge. The experienced inpatient knows which behaviors will reap certain responses from the staff on the ward. In the passage below, Martha refers to herself as a "pro" of the system:

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> I knew the system so well by now ... (laughing) This is a pro coming in. I knew that if I jumped out of my bed and ran down the hall that they would throw me in time out [a seclusion room]. And I couldn't stand my roommate I had. ...I didn't want to sleep in the same room, so I knew I could go sleep in time out ... I knew the system ... I knew how to get away from her (Martha Wright 1988).

Martha relies on the reactive feature in patient-staff relationships (i.e., Martha's erratic behavior "earns" her a place to sleep in the seclusion room) to secure what she needed at the time. As a "pro" of the system, she knows what rules she needs to follow--or violate--to have her needs met.

Other consumers who have had multiple admissions to the hospital expect hospital staff to intercede in known ways as well. When the expected response is not forthcoming, this may enrage a patient who, like Martha above, is following (or violating) the known rules to achieve response from the staff. When the ensuing rage is not acknowledged by staff intervention, patients' may find the disjunction between what is known (through previous experience) and what is being learned (i.e., violation of behavioral sanctions may not garner an expected staff response) unbearable and seek to end the experience altogether (i.e., attempt suicide).

When the initial rage arises, it is veritably palpable, as heard in the following excerpt from Alice Wetherby's interview. (I have emphasized portions of the text that illuminate Alice's relationship with the staff.)

> I sat there at the roof door ... for quite a while, and then I went back down. And *I was gonna jump off the roof ... end it right there ... just ... fly off and let them watch me. That's what I was considering because I was pissed at them.* ... They were having a meeting ...

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> right next to ... the music room. *I had just got done destroying the entire music room* ... I was throwing records across the room and smashing them ... I was just frisbeeing them across the room, hitting the metal [and making a big] CLANG ... *They had to have heard it* (Alice Wetherby 1987).

In this poignant passage, it becomes clear that when the hospital staff do not attend to needs perceived by Alice, a dangerous process ensues. She first destroys <u>things</u> (in the music room) but as the lack of attention continues, she considers destroying <u>herself</u> (by jumping off the roof). The altered definition of the situation (i.e., lack of staff response) has proved intolerable to her. In her anger, she constructs her suicide as an event that will hurt the staff, apparently because this would demonstrate to others how poorly these mental health care professionals protect those in their charge, and/or because they would feel saddened by their loss of her. It would also graphically communicate the pain and anger she experienced through their lack of response that she could not describe to them verbally.

Multiple admissions to the same hospital (and/or to the same psychiatric unit) lead to problematic relationships with the staff. This is related to the inconsistency with which the definition of the situation is applied by staff as well as consumers. Violations of certain behavioral rules are expected to earn certain sanctions (e.g., seclusion or attention). The sanctions are mutually defined as appropriate intervention within the context of the larger definition of the situation at work (i.e., staff are helpers and protectors and consumers are mental patients, needing help and protection).

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Extended contact with staff (through readmission to the unit) allow consumers to see that the definition of the situation is variable (i.e., staff are not always protectors, they will not always respond to certain violations of behavior). Because consumers still believe they need the help professionals offer through hospitalization, they cannot entirely abandon the definition of the situation presented to them by professionals. A certain ambiguity is experienced by consumers, who seek to play the game according to the (now known to be) variable rules. Thus, it is not surprising that consumers construct paradoxical understandings of personnel in the hospital, nor that their behaviors may vary according to presence or absence of certain staff (whose response is more or less predictable to the involved consumer).

Alice exemplifies this ambiguity in the following passage. We hear that staff become "a pain" when they intercede, and are admonished when they don't (I have emphasized these portions in the text). This excerpt also reveals that Alice's "career" as an inpatient has been firmly established: she tells me of an identity specific to her inpatient status, and also of the careful plans she makes to avoid a "too early" staff detection that might interrupt plans to harm herself. Alice has learned to ensure that the part of the definition of the situation that varies the least (i.e., staff are to protect patients from self-inflicted harm) can still be applied. She has learned to "protect" the vehicle she uses which still guarantees staff response.

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> R: I was known as the light-bulb thief.
> Q: What did you do with the light-bulbs?
> R: You bust 'em. And [when] you bust 'em ... you wrap it up in a towel and step on it, and it don't make a loud noise ... and you have all your glass right in your towel so you can quickly shove it somewhere if someone's coming. ...I've done everything from ... trying to hang myself to cutting myself or trying to stab myself [while in the hospital].
> Q: Did staff ever intercede, or a patient?
> R: Yeah. *The staff ... interceded ... and then they became a pain to me.* (laugh) They did. *They came in and did a room check.* The 15 minute checks.[1] Which, *you don't [find] them doing them on a regular basis* ... I would be [put on] 15 minute checks, sit it my room and literally watch the door, and it'd be shut for an hour ... They need to see you to mark it down [in your chart], and they don't do that (Alice Wetherby 1987).

Alice's behavior on the unit reflects her growing awareness of the variable nature of patient-staff relations. Some behaviors elicit negative sanctions and attention (e.g., harm to self) others achieve positive sanction and attention (bestowal of a special status, "light bulb thief"). Staff are a "pain" if they follow the rules governing appropriate intervention (and do room checks) and are remiss in their professional duties when they don't. In this tension, the paradoxical nature of her staff relationship emerges: staff need to be outwitted (by Alice, the "light bulb thief") in order to elicit a guaranteed response (attention after Alice harms herself). But they must always be held accountable to the definition of the situation they provide (i.e., staff must act to protect the patient at all times and do room checks).

As she learns the variable rules that apply to hospitalizations (e.g., sanctions against light bulb theft are inconse-

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[1] That is, "suicidal precautions," which require staff to check patients' every 15 minutes and chart their observations.

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quential; but sanctions against self-harm achieve staff response), she learns to plan her actions according to which hospital personnel are scheduled for work on the day she wishes to instigate her plans. When she says, in the following interview excerpt, that she didn't "want a problem" from the staff, it is difficult to tell whether she wanted to wait for staff who would intercede or if she was waiting for staff who wouldn't intercede.

> I had found a light-bulb. (laugh) ... I remember taking it down, and I wasn't going to tell anyone, and I wasn't sure if I wanted to do it that day or the next day because I didn't know what staff ...was gonna be [working] on [the unit], and I didn't want ... a problem (Alice Wetherby 1987).

Alice did tell staff she had the light bulb, and they did search her room for it because she could not remember where she had hidden it, but they were unable to find it. They found it only after Alice had used it to harm herself and called them because she was bleeding (Alice Wetherby interview 1987).

In these examples offered by Alice, it is apparent that her social construction of mental health providers involve the notion of "protection" (e.g., by allowing her admission to the hospital and preventing her from harming herself) as well as the contradictory notion of "persecution" (e.g., hospital staff "became a pain to me" when they protected me).

Other consumers with multiple hospital admissions follow similar routes to achieve attention from staff. They report they are unable to speak about their problems with staff, and resort to "acting out" or engaging in behaviors that will evoke a response from the staff.

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> Q: You said earlier you have impulses about hurting yourself. Did that ever happen in a hospital?
> R: Yes ... we used to swallow like straight pins and stuff like that.
> Q: Was there any special reason you did that?
> R: More for a response than anything else.... I know I personally did it when I didn't feel I could talk to [hospital staff]. Then I would act out or hurt myself in some way...which would force them to pay more attention to me or to talk with me (Dana Monroe 1987).

Thus, Dana demonstrates that she has learned the rules that apply in the hospital as well. Harm to self elicits staff attention. It is the one piece in the definition of the situation between provider and patient that proves nearly inviolable. Several other people with multiple admissions learned this rule.

In the passage below, Carly finds no way of verbally ex pressing that she is planning her suicide on a scheduled pass, so she engages in behaviors that will force the staff to pay attention to her.

> I was planning on killing myself, and I had the drugs in the hospital to do it with. And [I was scheduled to leave on a week-end pass] ... and I didn't know how to tell them that I was planning to kill myself so I sliced on my arm. So that they'd notice (Carly Willis 1987).

It appears that Carly was motivated to hurt herself to get the staff to notice her, as was true for Dana and Alice above. Unlike Dana and Alice, her "acting out" was also perceived as a means to secure staff help with an anticipated loss of control (i.e., a suicide attempt). Perhaps because her hospitalization experience was less extensive than others, her construction of staff-patient relationship relied more heavily on the rules defined by the professionals (i.e., we will protect mental patients from self-inflicted harm), and was therefore

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therefore less variable than Alice's construction of staff (as protectors and persecutors). It is noteworthy that Carly gained admission to the allegedly protected environment of the hospital with enough drugs to kill herself.

Infrequently, people who have had a series of hospitalizations will break the "revolving door syndrome" (i.e., recidivism) by a positive experience in the hospital. A positive hospitalization is related to the establishment of non-dependent, mutual respect relations with the hospital staff; particularly, ward therapists and/or group therapy leaders. Below, Martha relates an important turning point in her "career" as a mental patient (emphasized in the text). She learns to see the staff in a positive way after she is exposed to a woman on the same inpatient unit who was "very positive" about the staff and the help they accorded her.

> This [last] time, I was in the hospital with a ... woman [who] was really into believing that the staff was there to help her ... to protect her so she didn't kill herself. And she had to work through that with her members of the staff. They were constantly working with her, and *she was very positive about the people on the staff. And it rubbed off on me. And I started to say: well, geez, that's an advantage.* So, I would get up at night and ... I couldn't sleep, and they would say: do you want a sleeping pill? And I said: I'd rather sit and talk with you for a while. I would tell them ... what really ... brought me [to] the hospital was a lot of stress on the outside ... *I started to utilize the staff* and realize the ... advantage [in it]...they would tell you more if you were talkative and you seemed to be with it ... *If you're a nice patient, they will give you special treatment* ...if you get along with the staff, you get along much better (Martha Wright 1987).

Martha's experience is significant for several reasons: she modeled her behavior after another inpatient who was clearly "working things through" with the hospital staff; she learned tha

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learned that staff would "tell you more" if she was "talkative" and "seemed to be with it;" and that being a "nice patient" brought "special treatment." Martha learned to alter her definition of the hospital situation through this experience. Violations of behavioral rules which manipulated staff into providing her a night in the seclusion room (reviewed earlier) were not the only route to garnering staff attention or to getting her needs met. Honest disclosure to staff allowed a reciprocal relationship to develop, and the ensuing relationship had a positive impact on her.

Martha learns about the process of *empowerment* through acquisition of this new knowledge. She, like the woman acting as her role model, *becomes* a nice patient. She shares meaningful relationships with staff. By *altering the definition of the situation*, Martha begins to edge closer to eventual empowerment, i.e., she recognizes one route to implementing her own definition of the situation. She can speak out her needs rather than act them out, a necessary first step to eventual recovery (i.e., recovering the power lost when she deemed herself a "pro" of the system).

When Martha realized she could alter her situation by changing her behavior, she applied self-reflection to her situation. Through processes of self-reflection and modeling behaviors after a woman succeeding at altering self-destructive behaviors, she becomes a person who can and does change. These processes represent an evolving ability to implement a new definition of situation which can lead to altered definit

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definitions of self. (The ability to learn from other peers is a trait shared by persons involved at a high level with the Alternatives By Consumers organization. This theme will be elaborated in the following chapter.)

Boredom as an Inpatient Problem

Boredom is a problem endemic to mental health institutions, public or private, at local or state facilities. The pervasiveness of the problem was stated cogently by one of the consumers in the sample. When asked if boredom were a problem in the hospital, Bill sighed, then asked me: "How big is the world?" (Bill Peters 1987).

It appears that the problem is more severe for inmates at state mental hospitals, however. Dana was kept in a seclusion room for nine months as a teenager in a state hospital. She reflects on the problem of boredom in relation to her self-harming impulses. Note her use of the euphemism, "quiet room" in reference to confinement in seclusion.[1]

> Q: Was boredom a problem for you in the hospital?
> R: Yeah. (laugh)
> Q: Were there any activities at all, or?
> R: ... Not while I was in the quiet room. ...Because there wasn't anything to do, I'd think more about my problems ... Which would escalate to the point where I'd hurt myself (Dana Monroe 1987).

Thus, Dana has conceptualized boredom as a vehicle for escalation of self-harming impulses.

Although Alice does not make an explicit reference to it

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[1] This term, like "time out," is commonly used by hospital staff and consumers alike to refer to a seclusion room.

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in the following passage, her problems with controlling self-harming impulses (reviewed earlier) may be a function of the dynamic that Dana notes in the preceding passage.[1]

The following excerpt reveals the atmosphere on the second floor of the local hospital, to which Alice was usually admitted (as a public mental health consumer). From her description, it appears that most of the other patients sleep during daytime hours. Other consumers in the sample, like Alice, note that "week-ends are the worst" with respect to boredom. Note the comparison she makes between the public floor and state hospitals (emphasized in the text).

> Q: Was boredom a problem while you were hospitalized?
> R: Yeah. ... (laugh) Weekends is the worst. Weekends you have no daily things or meetings going on. ... Usually, it's people who've been up there for a few months know ... when to ask for things to do ... they try to do things ... like get card games going ... But the majority of them sleep because of the heavy doses of medications ... *Second floor is where most people who are committed go ... and it is ... the same as the [state mental] institutions: medicate them, and out they go* (Alice Wetherby 1987).

The portrait of the second floor communicated to us by Alice in this passage is one devoid of programmatic activities where many people sleep because of their medication dosage level. Alice implies a "seasoned (patient) status" by revealing her inside knowledge about the right time to ask for activity ideas.

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[1] At one point in the interview, Alice related a story about her early employment at Alternatives By Consumers, when a woman (with whom she had been hospitalized) asked if she was "okay enough" to assist her with a problem. Alice told her she thought so, adding "I'm too busy to be mentally ill" (Alice Wetherby, 1987). This echoes Dana's insight into the link between boredom and self-harming impulses, albeit from the other side of the fence.

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In the following passage, Steven Ashton expresses a sentiment is similar to Dana's (reviewed earlier): lack of stimulating activity allows people time for unabated introspection.

> R: Yes, I had a problem with boredom. I was bored all the time. I was bored in the community meetings, I was bored in group meetings, I was bored in ... Everything was boring.
> Q: There were some activities?
> R: (He nods.) But I was still bored. I was not stimulated by ... activities that ... never interested [me] in the first place. To be doing crafts, ... Or to ... be doing leather [work], ... or music was all boring to me, so [it] just breeded more depression for me (Steven Ashton 1987).

Activities that were meaningless to Steven did not attenuate the boredom he experienced. Thus, it is not only the presence or absence of activities that comprise the "boredom problem:" activities need to be meaningful to prevent boredom.

In the following excerpt, Sarah defines the problem of boredom. As she reflects on this, she makes connection between boredom and the condition of patients on the public consumer ward in the local hospital, then to the treatment provided patients with this condition. She wonders if this is the fate accorded to "vegetables" or worse yet, if "vegetables" define what she and her ward-mates will become. Little wonder that "fear arises" at this point for Sarah: if those who provide (or withhold) activities deem people on the ward "not worth an activity on the week-end," what <u>are</u> patients/(medicated) "vegetables" worth?

> There is no stimulation of any kind in the hospital. There's nothing to look forward to. ... It's like, we're sick, so we have to sit. What are we? Are we vegetables? Are we gonna become vegetables? Fear arises. Are we not worth an activity on the weekend? (Sarah James 1987).

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For Sarah, boredom attributed to a lack of provided activities communicates an insidious definition of self as "vegetable" (or potential "vegetable").

Below, Ben Harris responds with a system-wide perspective on the pervasive problem of boredom. He expresses insight into the insidious definitions of self that emanate from treatment in the public mental health system.

> Q: Was boredom a problem in the hospital?
> R: Definitely. Still is [even in outpatient programs] ... A big part of, mental health systems, in my opinion, have a tendency to operate at the lowest common denominator: "Let's get low enough that we can catch the majority." Okay? So ... they [tend to] operate all [programs] as if we all had an IQ of 50, that we are so dumb that [they need to keep] the schedules ... simple, so it's all boring (Ben Harris 1988).

Ben has included reflection on outpatient and inpatient mental health programs in this response. No substantial difference in the definitions of self that emanate from the various treatment programs is noted by Ben: public mental health consumers are: "dumb," not expected to handle complicated schedules or activities, and not distinguishable as individuals. Characterized en masse by these attributes, the programs developed to assist consumers in recovery provide no challenge for them. Limitations imposed by the bureaucratic structure of the care system cannot accord recognition of individuals. Thus, a predictable structural trait in programs entails boredom for consumers not captured by attempts to "reach the lowest common denominator" of the population.

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Local Hospital Differences: Private versus Public Floors

When examining consumers' responses to questions about hospital program offerings, the difference between those available on the public mental health (second) floor versus those available on the private mental health (third) floor become most apparent.[1] There are fewer programs and/or unit activities available to people on the public floor than on the private floor. Attendance at a medication group meeting is mandatory for patients on the public floor, whether or not they are currently taking psychiatric medications (Interviews 1, 11 1987). Emphasis on medications, administration of high doses of psychiatric medications for most patients, and lack of meaningful programmatic structure characterize consumers' experiences when admitted or committed for inpatient care to the public mental health floor.

In the following passage, Carly attributes a lack of activities and peer example as the reasons she started smoking cigarettes when she was in the hospital. She is unaware that smoking dilutes the effects of psychiatric medications.[2] She also provides a description of the difference in activity

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1.On some occasions, public mental health consumers are admitted to the private floor because no beds are available in the public area. This provides opportunity to compare the respective floors.

2."Heavy consumption of cigarettes requires larger doses of antipsychotics [major tranquilizers]," "Psychotropic Drug Therapy," *American Journal of Nursing,* (July) 1981, p. 1320.

This may explain a field observation during my research/employment at Alternatives By Consumers: nearly all mental health consumers in and out of hospital settings smoke heavily. This is frequently a point of contention with proprietors when consumers seek rental properties for drop-in centers.

level between the public (second) and private (third) floors in the hospital used most by consumers in this sample.

> R: On the private floor, we played basketball. We played volleyball. They went swimming, they went bowling. I didn't join in those. On the public floor, the only thing there was to do was listen to music, watch TV, crossword puzzles, which somebody brought in to me. And smoke cigarettes. When I ... started this hospitalization I was a non-smoker.
> Q: So you took up smoking as an activity? (laugh)
> R: (laugh) I took up smoking. ... Because everybody else was smoking (Carly Willis 1987).

Carly summarizes a significant finding in the research, namely that the private floor inpatients had a wide variety of recreational activities in which they could participate. Public floor inpatients, on the other hand, were rarely permitted to leave the floor to pursue recreational activities. Apparently, the known benefits of physical activity for people suffering from depression or anxiety are accorded only to private inpatients.

Below, Martha highlights another apparent trend in these data. Public floor inpatients dealt predominantly with "maintenance care" issues, i.e., housing and (Social Security Administration) disability benefits, "SSI" (supplemental income) or "SSD" (a benefit linked to previous employment) procurement.

> On second floor ... you don't get into resolving your problems. You get into maintenance care. Learning: now, what are you gonna do when you get out of the hospital? Are you gonna have a place to live, are you paying your bills, do you need to sign up for SSD or SSI? ... (Martha Wright 1987).

Martha has constructed problem-solving as something other than meeting essential needs for housing and income. If problems experienced by public mental health consumers do not include such

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include such "maintenance care" issues, they are not likely to receive close attention on the public floor.

Sarah was aware of the programmatic differences between the floors, as she was of the difference between the cohorts of patients on each floor. Below, Sarah lends support to Carly's comments about the difference in activities by floor assignment. She also supports Martha's comments by agreeing that the "SSI class of people" (on the public second floor) had different interests than third floor (private) patients. Sarah broaches a request for a change in the activity structure at a ward "community meeting."[1]

> Q: Do you see any differences between the floors?
> R: We brought that out at one of the community meetings one time. Hey, why can the third floor [use the hospital's van to] go bowling? We've [people on the public floor] never been bowling. ... Since that time they did. They've been bowling with them, ... going to the gardens. We never went anywhere, but third floor did.
> Q: Did you notice other things?
> R: Atmosphere. It's a lot more soothing.
> Q: The third floor is? Why do you think that is?
> R: Less people. Definitely. Less confusion. A different class of people. Let's face it. People [on the public floor], get SSI ... But [if you're on] SSI, you've never worked. You're not able to work. [There's] a big difference ... it's not that hectic, harried ... crazed, type atmosphere [on the private floor like it is on the public floor]. And, [people on the private floor] get movies more often cause it's less people, less hassle (Sarah James 1987).

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[1] "Community meetings" are held on a daily basis (except weekends). All inpatients are expected to attend the meetings, as are all available staff on the floor (i.e., therapists and/or psychiatrists, nurses and "psych techs" [psychiatric technicians] previously known as "orderlies"). The meetings provide an opportunity for patients to raise issues of concern to the entire "community" in the presence of staff, and provides staff with the opportunity to make general announcements affecting all patients. It is allegedly a "problem-solving" forum.

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We learn from Sarah that the private third floor not only has recreational opportunities, but they are also taken off grounds to pursue some of them. They also have movies (i.e., videos shown on a monitor on the ward) that second floor public inpatients do not. The difference in atmosphere is credited to the presence of more people on the public floor. Sarah implies that some of the differences noted are connected to the "class of people" on the public floor, who have not worked competitively,[1] and/or are not currently able to do so.

Psychotherapy: In-hospital, Public vs. Private

Martha reveals that the type of psychotherapy offered to inpatients, like activities, also differs by their public or private connection to the mental health system. "On the second floor, it was only group therapy ... And third floor was private therapy. Individual therapy. They also had [optional] groups [for therapy] ... on three" (Martha Wright 1987).

The difference in type of therapy available on the respective floors was noted repeatedly by persons with whom I interviewed. It seemed to be a contentious problem for many consumers who hoped that hospitalization, and expected opportunity for psychotherapy, would resolve some of their acute difficulties. Carly's comments, below, portray group therapy as the "worst part" of her public floor experience.

> The worst part about the public floor was being forced to go to groups with people that were obviously psychotic. I mean, I knew I didn't belong there. It ... was like I was

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[1] Competitive employment refers to non-sheltered work settings.

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> the only sane person on a floor full of crazy people ... I had to sit in those groups to avoid being in the locked [intensive care] area. One of the conditions for not being in the locked area was letting them take my vital signs, going to every group, and eating at mealtime (Carly Willis 1987).

Carly has highlighted a finding rarely made explicit among the mental health consumers interviewed. When she tells us that she was mandated to attend group therapy, it was not presented to her as something of value or meaning, but as a way to escape the isolation of the "locked area." She knew it wasn't appropriate for her, but her views were discredited in favor of a "behavior modification" approach which dominated many activities on the public floor (including attainment of privileges accorded by reaching certain "step levels").

In contrast to Carly's experience with public floor group therapy is Martha's experience with group therapy on the private floor, where she gained important understanding about recurring difficulties:

> On third floor [during group therapy], they came up with the idea that I'm very self-destructive ... I was in the group with three other women and we had stuff in common. We had all been abused or neglected as children and we were working that through ... it was more insightful than any [other] therapy I've gotten... it was really eye-opening ... I was neglected as a child, so now I have learned, because my mother isn't there, to do it myself. I can neglect myself like my mother neglected me. I learned ... stuff that could help ... and my psychologist [at the hospital] said: you're hospitalizations are a learned behavior (Martha Wright 1987).

It is significant that Martha received help not only from the psychologist she saw in the hospital, but also from other women in her group therapy sessions. The psychologist provided a (group therapy) setting in which the women could "work through" issues experienced as personal but seen in common.

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When Martha states that this was "more insightful than any other therapy," this may be connected to the revelation that issues are shared, which may not be as easily perceived in (the structured inequality of) one-to-one psychotherapy.

Individual psychotherapy relies on a definition of the situation where the therapist is an expert, providing advice, and the client is a person needing tutelage in the areas of the therapist's expertise. Some of this structural inequality may be assuaged by the personal characteristics of therapist and client, but some argue this is not possible. Jeffrey Masson (1988) is one such critic of psychotherapy. In *Against Therapy: Emotional tyranny and the myth of psychological healing,* Masson argues that:

> The structure of psychotherapy is such that no matter how kindly a person is, when that person becomes a therapist, he or she is engaged in acts that are bound to diminish the dignity, autonomy, and freedom of the person who comes for help....Blaming the victim is the hallmark of psychotherapy. The values essential to psychotherapy deflect a person from deep reflection on the sources of human misery....(T)he pretensions of psychotherapy are not accidental. By its very nature, [it] must pretend to supply an objective, kindly and humane atmosphere to those who wish to express their deepest feelings of pain and sorrow. The tragedy is that this legitimate need is exploited, even if with the best of intentions, by "experts" who claim to offer what has never been theirs to give" (Masson 1988, p. ix, 8, 9).

While it is difficult to refute Masson's claims, he assumes that psychotherapy is always a matter of choice. This is not true for many public mental health consumers, whose alternatives to psychotherapy may well entail incarceration in state hospitals, and far more damaging treatments (e.g., electroconvulsive therapy (ECT), psychiatric drug administraion, s

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tion, seclusion, physical restraint and even psychosurgery, still being conducted today[1]). If psychotherapy is not the best alternative, it is also unlikely to irrevocably damage brain or body. In this less than perfect world, if purchase of (or assignment to) a "caring relationship" is helpful or necessary to learn fundamentals of constructive relating to others, then so be it. For some consumers in this sample, psychotherapy seems to have operated in this way.

Group therapy, by contrast, evoked a variety of individual responses. Like Martha, Carly also had experience with group therapy on the private floor. Although different from her experiences with public floor groups, they were also problematic:

> On the private floor, it was group therapy. Because, I mean, you're looking at a person who never, ever, ever looked at her feelings before. I was very shy and they wanted me to talk about all these things in front of a group of strangers. And it's like, forget it. I just shut right down. I wouldn't (Carly Willis 1987).

Several consumers in the research sample made reference to the problem of dealing with intensely personal issues in the presence of "strangers."[2] For Carly, uncomfortable feelings about this made her "shut right down." Other people who experienced similar difficulties were helped in large measure by overtures made to them by the staff. Not surprisingly, consumers in the sample also identified significant differ-

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1.See e.g., Valenstein (1986, 284-290).

2.This finding is reminiscent of Georg Simmel's claim that "elements which increase distance and repel, in relations of and with the stranger, produce a pattern of coordination and consistent interaction" (Simmel in Wolff 1950, 403).

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ences between staff persons employed on the public floor versus those working on the private floor.

Staff Differences: Public vs. Private

All consumers who had been on both public and private floors offered comparisons between the respective floor staff when simply asked to "characterize hospital staff" during the interviews. In the following passage, we find that Connie withdrew from others, especially staff, because they were not known to her (evoking a similar notion of "stranger" alluded to by Carly in the previous section). She was appreciative of staff efforts on the private floor to seek her out.

> When I was on third floor there was at least three [staff] people that I felt that I could talk to. I felt that even though ... I didn't feel that I could come out [of my room], they would come and talk to me and ask me: are you okay? Do you want to talk or do you need something? ... A lot of people are scared of going and talking to [staff] people because they don't know who they are. So, that is one thing that did seem good at that place ... on third floor (Connie Hawks 1988).

For inpatients used to routines on the public floor, the private floor staff initiative to seek out reclusive patients and determine what kinds of help could be offered to them was remarkable. Other consumers revealed that staff demeanor on the respective floors was purposefully structured in certain ways. Alice notes this below, with respect to "psych techs" (psychiatric technicians) on the public floor.

> On the [public] floor, ... the ... psych techs are instructed not to have in-depth conversations with anyone. Yet, you can't get anything done without talking to your point person, which is a psych tech or a nurse (Alice Wetherby 1987).

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The structured eschewal of patient-staff conversations on the public floor created a dilemma for patients attempting to follow the rules of the ward. Each patient is assigned to a "point person," a staff member who will be available for individual issues arising with their assigned patients. For patients assigned to a "psych tech point person," the structure of the ward prevents needed in-depth discussion.

Dana illuminates an apparent reason for this restriction:

> R: Usually ... on second floor, the staff aren't supposed to talk to people because it's more of a med [medication] adjustment floor. Third floor, they'll usually talk to you a little more. Usually if you're having a problem, [second floor staff] tell you that they ... can't talk to you, that you need to talk to your therapist.
> Q: And that wasn't very helpful?
> R: No. (laugh) Because it would be like 8 or 10 hours before you'd see your therapist or your therapist would come back on shift or whatever (Dana Monroe 1987).

Dana believes that psych techs are "not supposed to talk to people [on the public floor] because it's a med adjustment floor." What does this communicate to the person? For Dana, it appears that providers have structured the environment of the public floor for the sole provision of medication adjustment. The staff "aren't supposed to" have personal relationships with public consumers. Apparently, personal relationships with staff are within the purview of private floor patients only. Consumers on the public floor are "supposed to" hold any need for a meaningful relationship with mental health providers in abeyance until a therapist assigned to the consumer makes a scheduled appearance on the floor.

Sarah extends the theme Dana has touched on, i.e., there is a striking qualitative difference in how people are cared for by

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> I've even noticed a difference in the employees themselves. They don't have any big burly dudes that scare the shit out of you [on the private floor] ... Well, as a matter of fact, when I admitted myself to the third floor, I said: I just can't do it anymore. I said: I'm a bundle of nerves. I'm vomiting. You know, the headaches. Stomach. The nurse said: oh, for heaven's sakes, why didn't you come in sooner? ... You just don't get that kind of stuff on [the public] second floor (Sarah James 1987).

It is noteworthy that the hospital assigns (or hires) larger staff people for the public mental health floor, which is Sarah's impression. With many of the second floor patients on high levels of psychiatric medication, and in the absence of physical activities that might assuage anxieties inpatients may experience, perhaps large people are needed to enforce social control when the structures in place (medications, locked areas, seclusion rooms and meaningless activities) do not suffice. The empathy that third floor staff manifests in the above exchange with Sarah departs dramatically from bureaucratic mandates which preclude such interactions on the public floor.

In the following passage, Carly provides an overview of the second and third floor staff characteristics. We are made painfully aware of the lack of empathy from second floor staff in her comments.

> With public floor [staff], ... you could tell what kind of people they were. On the night shift, they were students. On the day shift, the counselors acted like they were burned out. They were punitive ... The direct care workers were derogatory. One of them told me: I can't believe you're a [health care professional]. I had a nurse tell me once that: if you'd a really wanted to kill yourself, you would of done it. It was not very conducive to gaining your health back, I'll tell you that much. They ... shamed me ... (Carly Willis 1987).

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Carly has thus characterized the public floor staff as inexperienced ("students"); exhausted by the demands of their job ("burned out"); recriminatory ("punitive and derogatory"); and judgmental. Moreover, the staff have constructed a veritably fatal message for Carly: "If you'd a really wanted to kill yourself you would of done it."

Carly was admitted because she tried to kill herself. Thus, she (currently believes that) wants to kill herself. Moreover, the "would have" opportunity is gone. Carly can only act in the present or future: she can or will kill herself. The construction becomes: if you want to kill yourself, you will. Having been invited to believe that if she really wanted to kill herself she would, she tries to meet the expectation of the mental health care professional. She barely survived her next suicide attempt, and required constant monitoring in the non-psychiatric, intensive care section in a medical hospital. Brain damage from her attempt was barely averted, and in question for several days (Carly Willis 1987).

This analysis is informed by "an etiological hypothesis [expressed by Jourard (1971) and] shared by increasing numbers of behavioral and stress researchers; namely that human sickness versus health is largely dependent upon noxious interpersonal variables, presumably related to pathogenic anxiety and stress" (in Teixeira 1984, 377). Jourard states:

> When a person feels he [she] cannot live anymore in the way that he [she] has been, when he [she] feels trapped in frozen interpersonal relationships in a social system that he [she] feels offers him [her] no way out, he [she] may fall physically ill, become schizophrenic or psychotically depressed ... or commit suicide. ... I propose that *people*

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> *destroy themselves in response to an invitation originating from others to stop living.* ... Dying can be seen fruitfully as responses to an invitation ... extended by others. ... In whatever mode the wish for death or the indifference to continued existence exists, it is communicated to the one whom we might call the *suicide.* He [she] experiences himself [herself] as being invited to stop living, and he [she] obliges (Jourard 1971, 92-100 in Teixeira 1984, 378).

Carly's reflection that this was "not conducive to gaining [my] health back" seems a generous understatement of the effect that these social constructions of suicide intent subsequently had on her.

In the passage below, Carly identifies the assumptions that undergird differential treatment on the two mental health floors at this hospital:

> The only thing to say ... is that there's an obvious difference [between floors] in the way people are treated. *On the private floor, you're treated like a human being who has problems.* At least you get the impression that people there are trying to help you. *On the public floor, you're treated as a behavioral problem.* ... There really is nothing, I can't think of anything therapeutic that happened on the public floor. Not one single thing. Except maybe the thing that saved my life: an employee on the public floor gave me her phone number and told me she'd take me to an AA [Alcoholics Anonymous] meeting (Carly Willis 1987).

Carly captures the sentiments of other consumers in her portrayal of treatment accorded consumers on the respective floors. When staff on the private floor take initiative to talk with patients and communicate emphathetic understanding, this constructs the message that they are cared for as human beings. In contrast, when patients on the public floor are medicated to the point of lethargy, and denied physical recreation and meaningful activities, this communicates an entirely different message: public consumers are behavioral problems.

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It is significant that "the thing that saved [Carly's] life," i.e. the invitation to accompany one of the public floor nurses to an AA meeting, was undoubtedly a violation of bureaucratic rules prohibiting staff-patient outside contacts.[1]

Jeff Bell's depiction of the difference between treatment accorded patients on the respective floors is an anomaly in this sample. His impression is that consumers on the private floor are more heavily medicated than those on the public floor; and that those on the public floor don't receive medications unless needed. He also counters the voiced opinion of staff on the public second floor:

> It isn't so much with me on the third floor, but they tend to heavily sedate people more on the third floor to keep the country club atmosphere. And the second floor, they let people act out their aggressions if they need to (laughing). Somehow, the second floor, ... is better in a sense because they try to help you deal with things and don't shove drugs down your throat unless you absolutely need them (Jeff Bell 1987).

Jeff's observations tend to support previous comments that characterize the private third floor as "soothing" and "less confused" (Sarah James 1987). Moreover, a "country club atmosphere" more likely characterizes a unit that has fewer people (Sarah James 1987; Carly Willis 1987; Dana Monroe 1987; Alice Wetherby 1987). Martha also noted that one of her two choices for group therapy on the private floor involved one group where "the patients were so drugged up... they can't remember their name, practically" (Martha Wright 1987). This tends to

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[1] As communicated to me by consumers in the sample (Interview numbers 1, 5, 8).

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support Jeff's statement that patients were "heavily sedated" on the floor, but whether the third floor was <u>more</u> medicated than the second is difficult to discern in an atmosphere were nearly all patients on either ward are receiving major psychiatric drugs.

However, Jeff's other observation that second floor staff "help you deal with things" is not supported by others in this sample. This observation is not easily explained, although a number of variables may be intervening: high number of public floor hospitalizations for Jeff, allowing time to establish a different kind of relationship with staff; limited exposure to the third floor which skews his observation by a possible "outlier" effect; his embrace of a medical understanding of "mental illness"[1], in likely accord with most of the staff with whom he interacts when hospitalized; and personality characteristics that affect interactions. It is unlikely that his experience is related to gender since other men with hospitalization experience on the public floor support the staff differential noted by the women in this sample.[2]

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[1] During the interview, when asked to provide a definition of "mental illness," Jeff states: "Basically, [mental illness] means I was born without the X chromosome marker 11 that fluctuates my biochemicals in my body. ... The basis of my illness [is] really ... biochemical" (Jeff Bell, 1987).

[2] Small sample size, combined with a preponderance of women in the sample, do not allow informed speculation on the affect of gender in Jeff's observations.

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Electroconvulsive Therapy (ECT)

Pamela Martin was one of two people[a] in the sample who has had ECT, "electroconvulsive therapy" (more commonly called electroshock or shock treatments). She was under 18 years old when she received ECT in a local community hospital for reasons unknown to her. This treatment continues to be provided by psychiatrists in the city, as Pamela correctly points out. It may be significant that she responds to my question concerning additional ECT treatments with "not to my knowledge," since the hallmark "side effect" of ECT is loss of memory: "ECT produces brain hemorrhage, cerebral edema, and toxic effects resulting from the brain's being exposed to chemicals in the blood that it was ordinarily protected from by the blood-brain barrier. All of this leads to death of brain cells, which results in memory loss, often of a severe and long-term nature" (Brown 1985, 161).

> Q: Do you know why they gave [ECT] to you?
> R: No. ... Then I was into the state that ... I figured whatever they was trying to do to me [they'd do], so I just gave up. And whatever they wanted, I done. And I never questioned it ... until later ...
> Q: How long did it go on?
> R: It goes on a cycle for about six months. I used to get 'em ... twice a week. It was here ... in Lansing. As a matter of fact, he still does 'em as far as I know ... But the other doctors, they don't think that it's right, so.
> Q: What did you think about it?
> R: (laugh) ... I don't know, they were adults. And I figured I wasn't, you know? I figured that they ... knew what they were doing ... that it was best for me ... Because I was still signed in [to the hospital] under age [i.e., under 18][1], signed in by my parents.
> Q: But you never got them again after that?
> R: No, not to my knowledge (Pamela Martin 1987).

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[1] This places her ECT experience in the early 1960s.

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Pamela's response to my question concerning her opinion of ECT reveals an obsequiousness common to early hospital experiences, i.e., the adults "knew best" what constituted appropriate "treatment." By citing what other local doctors think of ECT and noting that she "never questioned it, until later," Pamela implies that she would question it if it were prescribed for her again. Moreover, as an adult inpatient she would (more) likely be accorded the right to refuse such treatment.

Jeff recalls the effect on ECT for other patients with whom he was hospitalized. His sardonic observation about ECT aftermath is credible: Max Fink, a vocal proponent of ECT, has linked the effect of ECT and all major psychiatric treatments to the production of brain disability. "Lobotomy, insulin coma, ECT, and [major tranquilizers] all 'induce appreciable changes in brain function, including perception, mood, affect, memory, judgment, and attitude.' ...The alteration in brain function is not a 'complication' or an 'untoward effect' but the 'desired goal'" (Fink 1957, 1979 in Breggin 1983, 153).

Q: Did you ever have shock treatments?
R: No.
Q: Did you know people who did?
R: Yeah. Toasted to a crisp.
Q: Did you see anybody, like, before and after?
R: Before, there was no reason for them to be in a psych ward. After shock, there was plenty of reasons for them to be there.
Q: Was this in Lansing too?
R: Yeah (Jeff Bell 1987).

It is significant that both of these ECT incidents occurred in a local community hospital, despite the 20 year span between them. When the movement away from ECT was most vocif-

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erous in the local area (in the late 1970s), one psychiatrist administering ECT in Lansing was "shut down" due to local complaints levied against him by psychologists and mental health consumers in this locale (personal communication, Steven Ashton, 1986). Since that time, there has been a trend toward providing ECT in for-profit community hospitals and away from its provision in state facilities (see Brown 1985, 159-162). As part of this trend, ECT administration has returned to this community as well.

Outcry over ECT use in state mental hospitals has not ended the practice, it has merely forced its relocation to local centers. Moreover, its use is on the rise among private consumers of mental health services (Community Support Systems in-service educational session 1988).

Conclusions

Findings of this study reveal that treatment outcomes are shaped by a host of factors that impinge on an individual's experience of his or her prescribed treatment regime. Some of these factors are related to effects of social structure; some to the effects of the shared nature of the experience; and some to the effects of personal characteristics.

The social structure of the mental health system allows mental health professionals and/or providers to advance a certain definition of the situation for mental health consumers. This is particularly true for public mental health consumers whose treatment options are circumscribed by their financial position. The definition relies on professional

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authority to determine (and frequently enforce) "appropriate" treatments presented as beneficial to involved consumers, especially with respect to hospitalization and administration of major psychiatric drugs. The definition of the situation also accords professionals superordinate status, allowing a discrediting of consumer perspective (vis-a-vis subordinate status) over these same issues.

The effect of bureaucratic structure on treatment experiences was also significant. It has been found to affect the frequency of changes in assigned (or accessible) therapists; the quality of coerced psychotherapy; the nature of programs developed for consumers; and the kind of permitted interactions between staff and patients on private versus public psychiatric wards.

The social position of consumers labeled "chronically mentally ill" intensifies the authority allowed to professionals. Data reveal that for this sample of people deemed "chronically mentally ill," outpatient and inpatient psychotherapy; hospital admission or refused admission; and variable treatment from inpatient staff are affected by this attribute.

Assumptions predicated on the differential nature of public consumers (e.g., seen as "behavioral problems") versus private consumers (e.g., seen as "human beings with problems") affect the respective program offerings in the hospital as well. Private patients are given opportunities for a wide range of activities: group psychotherapy that delves into analysis of personal dynamics; opportunity for individual

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psychotherapy while hospitalized; craft activities; movie viewings; and recreational activities and/or outings. Public patients are not allowed opportunity for recreation nor private psychotherapy, and attendance at groups dealing with psychiatric drug use is mandated, whether the consumer is taking such medications or not. Boredom is a problem related to hospitalization, regardless of public or private categorization. However, the increased likelihood of boredom for public patients, with fewer meaningful programmatic opportunities, has been found to exacerbate troubling conditions for some consumers. Thus, potential for boredom to cause harm is increased for consumers relying on public mental health care offerings.

The shared nature of consumers' experience provides important opportunities for them to observe each other in treatment settings. This opportunity may awaken possibilities of empowerment in certain individuals, who receive new knowledge and may apply it to alter the definition of their received situation (as when modeling their inpatient behaviors after others who are clearly on a path to recovery). Other times, the exchange of peer knowledge serves to entrench definition of self as "mental patient" (as when members of a support group, exclusive to one diagnosis, maintain certain definitions of the "illness" and its "necessary" treatment). Other consumers are affected by group treatment settings by learning they are negatively defined by providers (as indirectly communicated by staff and/or program practices) and reject these perceived definitions, which may allow them to alter

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alter their definition of self. Personal characteristics impinge on strategies selected for coping with treatment within the mental health system as well.

The Alternatives By Consumers organization also allows a shared experience for consumers. The effects of consumer interaction in a setting <u>not</u> structured by imposition of professional definition of the situation depart dramatically from experiences in shared treatment settings. These departures are the focus of the next chapter, which examines the Alternatives By Consumers' community.

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CHAPTER END NOTES

(a)Regrettably, my tape recording of the other direct experience with ECT among mental health consumers in the sample was "eaten" by my tape recorder. I fear that I would inaccurately recall details of the experience for this person, so references to it are omitted in this chapter.

CHAPTER 7

EXPERIENCES AT ALTERNATIVES BY CONSUMERS

Introduction

The contention of this chapter is that experiences at the consumer-run organization Alternatives By Consumers (ABC) allow mental health consumers to alter their definition of situation heretofore provided by mental health professionals in treatment settings. That is, the workings of this organization contribute to possibilities of change in self identity, from "mental patient" to "consumer advocate." It appears that several people in this sample have effected a change in self-identity; others appear to be in a "transitional period," neither advocates nor patients, and others have not yet dislodged the notion that their primary identity is constituted by the appellation "mental patient."

To discern what differentiates these various categories, one central question is posed: How does participation in ABC alter definitions of self received in the mental health care system? To address this question, the nature of consumers' experience at ABC will be examined in the following pages. The foci of the discussion include: an overview of interactional

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dynamics at ABC affecting participants; network linkages that brought consumers to the organization; the patterns of first contact with the organization that suggest connection to subsequent levels of involvement; typical interpersonal interactions among participants at the organization; the development of reciprocity in relationships; instances of reflection about changes in identity accorded to ABC participation; the "backward glance" as an expression of changed identity; and use of social distancing as a marker of identity. Data reveal that assumptions about the nature of mental health consumers are communicated directly and indirectly to participants during interactions at ABC.

It is argued that the press of these social dynamics alter the definition of self through key elements: a high level of ABC-related activity, significant investment of time in pursuit of these activities, and interactions characterized by consumers' mutual support and acknowledgment. This latter feature may be most important during early exposure to ABC, as it affects subsequent commitment to or identification with the ABC community.

Overview of ABC Dynamics: Defining the Situation

Interactions at Alternatives By Consumers' (ABC) on the intra-organizational level (consumer-to-consumer) and inter-organizational level (ABC to system) involve attempts to alter the "definition of the situation" presented by mental health care providers and/or consumers. Examples include: questioning the authority of mental health system providers; questioning

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appropriateness or effectiveness of specific mental health care treatments; and reflecting about criteria for "mental illness," specific diagnoses, and/or "mental patient" status attribution.

Analyses reveal that consumers experience alteration of the "definition of the situation" in a non-linear fashion. As people are drawn to the ABC community and become active participants in the work of the organization, a changed definition of self from "mental patient" to "consumer advocate" may slowly evolve. The temporal element is fundamental for this evolution; it accounts for findings that suggest length of time with the organization and capacity in which the consumer is connected to the organization (e.g., staff, volunteer, guest) are important components in self-identity processes.

My analyses indicate that the "clusters of practices" that demarcate the "role" of mental patient[1] (e.g., admission and readmission to psychiatric inpatient care, emotional dependency on mental health providers, eschewal of meaningful personal relationships) are affected by participation in ABC. As consumers advocate with or for their peers, meaningful relationships ensue and become more important to daily life. Participants at ABC express this relation simply: "When I

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[1] This discussion is informed by Anthony Giddens' theory of social systems, which he presents as "not constituted of roles but of (reproduced) practices" (Giddens 1979, 117). The point of articulation between actors and social structure is found in the interplay of practices, role prescriptions, rules and resource allocations. "Roles can only be satisfactorily conceptualised in relation to practices" (Giddens 1979, 118).

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could help other people, it helped me, too." As the length of time spent working with the organization increases, a sense of community is realized. People formerly isolated and detached from activities in the larger community become enmeshed in the ABC community, where they are acknowledged as "people first and people with problems second" (Ashton, "Gentle Justice" video, 1988). They are seen and heard. In this process, the *practical experience* of their "mental illness" changes, and coping difficulties (routinely referred to as symptoms by practitioners) lessen in intensity and frequency.

This latter finding is grounded in the inductive analysis of interview data. "Practical experience of mental illness" is my way of conceptualizing the "practices" (i.e., coping difficulties) that consumers manifest during times of psychiatric hospitalization and/or those clusters of actions and belief by which they understand their emotional problems, communicated to me during the interviews.

In time, ABC participants come to emphasize the cluster of practices involved in their "role" of consumer advocate more than those clusters of practices involved in their (ascribed and/or internalized) "role" of "mental patient." This change of emphasis in the various social categories that contribute to their social identity allows a different sense of self to be experienced. Thus, "mental patient" as one aspect of a social identity comprised of many other identities (e.g., friend, neighbor, son, worker, parent, etc.) is downplayed as "consumer advocate" is accorded higher priority.

William Faunce (1981) complements this understanding of a shift

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shift in self-orientation as it connects to activities pursued by members of social organizations. Faunce suggests that identification with or commitment to a social organization originate as members are positively evaluated according to socially valued criteria recognized by the organization and used by members for evaluations of self (Faunce 1981, 138).[1] "...Support from others is required to confirm a favorable evaluation of self" (1981, 139). Thus, the more actively people engage in activities that are valued by the social organization ABC, the more likely they are to be positively evaluated by other members. Faunce states this relation in diametric terms:

> People who *remain* in situations where criteria used in assigning status are different from the criteria they use in self-esteem maintenance ... will minimize their expenditures of time and energy in the situation in order to conserve time and energy for what they regard as more important activities (Faunce 1981, 138-9). (Emphasis in the original.)

Based on this conceptualization, it is plausible that mental health consumers in ABC who are staff and/or daily volunteers for the organization would identify strongly with the values of the organization, devote substantial amounts of time and energy to pursuit of these values, and consequently be accorded high status within the organization because they

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[1] "The major values that shape our personalities (the criteria used in self-esteem maintenance) would be the same values that shape the organizations in which we are a member (the criteria used in status assignment). We would be motivated to achieve goals that are valued within these organizations because it is through the resulting status recognition from others that we confirm our own self-assessments" (Faunce 1981, 138).

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are evaluated by others according to these shared values. Their status at ABC would be higher than that accorded to guests by other members of the organization. High status ABC individuals could be expected to offer self-identity constructions during the interviews more closely aligned with "consumer advocates" than "mental patients," in efforts to maintain positive self-esteem garnered through ABC work.

I did find these clusters of factors as a pattern in some interviews. Seven people (of fifteen in the sample) whose primary identity at ABC was most consistently constructed as "consumer advocate" were all staff or former staff; volunteers or former volunteers (3-5 times/week), and associated with ABC for longer than 2 years. However, this trend was not apparent for three other people in this fashion, despite the similarity in their positions at ABC and length of time they had been involved with the organization.

This alerted me to the salience of other features in consumers' experiences that stymied a more positive evaluation of self and precluded embrace of "consumer advocate" as a primary feature of their social identity within the ABC community. One aspect of ABC's advocacy approach seems to affect this process.

The operationalized philosophy of the organization, i.e., its pursuit of "gentle justice," affects consumers' abilities to reflect upon specifics of their situation (labeled "mentally ill") and/or their diagnoses. This is indicated by close alliance between consumers' definitions for "mental illness" and definitions contained in the social stock of knowledge,

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revealed in interview responses. (These are reviewed later in this section.)

One manifest meaning of justice for mental health consumers at ABC is validation of their right to refuse or engage in treatment offered by mental health system practitioners and providers. In this validation process, (self and/or group) reflection about treatment experiences and provider practices occurs. But the question of the right to refuse or engage in treatment is qualitatively distinct from the question of whether the treatment itself is valid, or whether the condition of "mental illness" is amenable to treatment, or whether "mental illness" even exists. The question of just treatment for specific individuals presupposes existence of a treatable condition. Thus, their understanding of the condition for which treatment is received, in general terms like "mental illness" or in specific diagnostic terms, is not subject to the same reflection initiated by wondering whether treatment is just.

Social Knowledge: Intersection with ABC Dynamics

Social constructions of reality have an impact on consumers' understanding of "mental illness." The sociocultural characterization of certain human conditions or behaviors as manifestation of "mental illness" pervades society. Coping difficulties troubling to self or others are routinely defined as "mental illness" by professionals in the mental health field and other social scientists, news reporters, TV and movie script writers, neighbors and relatives, consumers and non-c

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non-consumers of mental health services.

Thomas Szasz (1987) identifies the "currently accepted criteria of mental illness" that pervade such professional and lay definitions by this listing:

Criteria of Mental Illness[1]

Proven brain disease
Putative brain disease
A species of medical disorder
A treatable condition (of brain or mind)
Distress, disability, disadvantage
Normality, unhappiness, suffering
Commitability
Nonintentionality
Irrationality
Irresponsibility
Deviance and crime
Other, miscellaneous criteria

For purposes of this discussion, these criteria will represent social knowledge about "mental illness" defined by the social stock of knowledge.

The conceptual layers articulated in definitions of mental illness involve relevances specific to social situations in the larger society. Sociology of knowledge theorists illuminate the connections between knowledge of everyday life "relevance structures" as they intersect with relevance structures of other people and those of the social stock of knowledge:

> My knowledge of everyday life is structured in terms of relevances. Some of these are determined by immediate pragmatic interests of mine, others by my general situation in society. ...However, my relevance structures intersect with the relevance structures of others at many

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[1] In Thomas Szasz (1987, 49).

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> points. ...An important element in my knowledge of everyday life is the knowledge of the relevance structures of others. ...The basic relevance structures referring to everyday life are presented to me ready-made by the social stock of knowledge itself. ...Finally, the social stock of knowledge as a whole has its own relevance structure (Berger and Luckmann 1967, 45).

Knowledge in everyday life is socially distributed (Berger and Luckmann 1967, 45): People in different social positions possess different types of knowledge, and there is a shared understanding of persons expected to have certain types of knowledge. Mental health professionals, for instance, have expert knowledge about what constitutes "mental illness" and/or its sub-types (i.e., diagnoses). Mental health consumers also have expert knowledge about the constitution of "mental illness" or its sub-types based on experiences and subsequent labeling of these experiences. According to dominant relevances of this society, professionals' expert knowledge is correct, achieved through objective appraisal and formal study. In contrast, dominant relevances of this society decree that mental health consumers' expert knowledge is incorrect, depending only on subjective appraisals of problems deemed to be private troubles.

However, the most salient feature in the relationship between providers and consumers is the status distinction of professionals. As ABC participants reflect on these relationships, they attend to relevance structures which perpetuate the quality of the relationship, despite their desire for improving these relationships. Their situation vis-a-vis their providers remain largely unchanged. Their situation vis-a-vis their peers, however, changes because the professional status

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distinction, which structures hierarchical relations, does not apply at ABC. Relevance structures at ABC embody notions of status accorded by nearness to or departures from the socially valued criteria of the organization: honest disclosure, interrelatedness, and appreciation of all persons' human dignity, regardless of their current level of coping difficulty or manifestation of emotional trouble.

Pragmatic concerns and assumptions about relevance structures of others also relate to social position and status. For example, many mental health professionals[1] attend to dominant relevances affecting services to clients. These include gender, race, and class of clients' but are also affected by relevances enabling or constraining their own situations, e.g., professional status, cost effectiveness of services proposed, and assumptions concerning human nature embodied in treatment prescriptions and/or planned programs. On the other hand, mental health consumers are attuned to dominant relevances affecting their situations: e.g., gender, race, class (of themselves and their providers); "mental patient" status attribution; treatment costs; treatment accessibility and/or availability; and assumptions concerning human nature through which they understand practitioners, other consumers, treat-

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[1] Freidson (1987) observes that professionals are selective in their application of formal knowledge, which also affects their attention to "dominant relevances" vis-a-vis clients. "...For both administrator and practitioner the substance of the formal knowledge selected or rejected for use is likely to be strongly influenced by the power, interests, and knowledge of the clients they serve" (Freidson 1987, 220-1).

ments, and their own responses to all of these.

Although coping difficulties may lessen as consumers become invested in the community ABC affords, their definitions of "mental illness" and professionals who treat conditions labeled in this way are generally characterized more by their internalized knowledge about dominant relevance structures in the shared social stock of knowledge than they are by their attachment to nascent relevance structures of consumer advocates.

One would expect, for instance, that consumer advocates might question the relevance structure of society that posits need for a professional, bureaucratic system of mental health care treatment vis-a-vis their experiential knowledge of relieving coping difficulties through peer-to-peer problem-solving efforts. Consumer advocates in this sample, however, posed their constructions of self-as-advocate predominantly within the confines of the ABC community and/or when acting behalf of other persons at ABC or an ABC-affiliated consumer-run organization (i.e., the satellite drop-in centers spawned by ABC's OUR Project).

There were expressions of interest in changing the <u>quality</u> of interaction between consumers and providers but noticeably few comments that suggested the structure of mental health care should be altered. In essence, consumer advocates focused on issues of reform rather than abolition or revolution. Their emergent sense of changed identity, from patient to advocate, remains tied to the dominating relevance structure of their own position: mental health consumer. (This is

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clearly seen in the suggestions for changing the system of mental health care, offered by ABC participants in the next chapter.)

There is remarkable convergence between consumers' suggested criteria for "mental illness" and those offered as "currently acceptable criteria" by Thomas Szasz (1987, 49). A *species of medical disorder* and a *treatable condition of brain or mind* are identified as criteria of "mental illness" for consumers who allude to biochemical, chromosome deficiencies and/or other treatable conditions (Interview numbers 1, 3, 4, 5, 8, 10, 12, 13). *Distress, disability, disadvantage;* and *normality, unhappiness, suffering* are also alluded to my consumers who mark "mental illness" by having problems or difficulties coping with everyday life situations and also by those who credit living in poverty as contributory to the "illness" (Interview numbers 1, 2, 4, 5, 7, 9, 11, 13). *Commitability, nonintentionality* and *irresponsibility* are criteria identified by consumers who see "mental illness" as beyond the control of the individual, whose commitment to the psychiatric hospital depended on actions of others, and by those who sought hospitalization because they could not care for themselves (Interview numbers 1, 2, 3, 4, 5, 6, 10, 13, 15). *Deviance and crime* appear as criteria of "mental illness" when a continuum of behaviors is posed as a marker, where brutal or violent behaviors connote severity of "illness" (Interviews numbers 1, 2, 6, 12, 15). *Miscellaneous criteria* for this sample include possibilities that people are possessed by spi

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It is also noteworthy that people whose degree of involvement with the Alternatives By Consumers organization is characterized as high (i.e., staff or regular volunteers) and/or whose length of connection to the organization exceeds 2 years are among those who deny the existence of "mental illness." Mental health consumers claiming "there is no such thing as mental illness" are, in effect, denying that this particular "relevance structure" is germane to their social position, but apply the term to convey a specific experiential condition when their own "relevance structures" intersect with the dominant "relevance structures" of society. Consider these responses:

> Q: Do you believe there is such a thing as mental illness?
> R: No.
> Q: Do you ever use the phrase mentally ill when you're talking about this population?
> R: Yes, I do.
> Q: What do you think of when you use that phrase?
> R: I don't know. It just automatically comes out. ... Sometimes, I ... watch the people [in the drop-in] and I say: ... whatever their problem was ... a lot of them bring it on themselves or ... maybe they don't think like I do. ... But some of them act like they don't want to get better, they want to stay like this (Karen York 1987).
>
> There is no such thing as "mental illness." Somebody like Charles Manson is mentally ill, but the word's too good for him... There is emotional disturbance ... and that's how I see myself (Connie Hawks 1988).
>
> R: I cannot give you a definition of mental illness because I don't know what mental illness is.
> Q: Do you believe there is such a thing as mental illness?
> R: The only thing that I ... No, I don't think there's such a thing as mental illness (Steven Ashton 1987).

As seen in the first two excerpts, ABC participants who ave

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aver that there is "no such thing as mental illness" nonetheless refer to behaviors or people that can be judged "mentally ill." Although they offer no definition for the condition, it is clear that they can apply the concept in practice. Below, Steven Ashton applies the term to himself at two different points in the 1987 interview.

> I didn't know that I was mentally ill....until I went to a social security hearing and then they had me labeled as borderline-schizophrenic...(Steven Ashton 1987).
>
> And then CETA came along....and I applied for that, and I got the job cause they wanted somebody that was mentally ill, and there I was (Steven Ashton 1987).

In these passages, Steven uses the term "mentally ill" without qualification. This is unusual. He routinely does qualify these terms, e.g., "labeled mentally ill," or "so called mental illness." He may have opted to use the term as a "short-hand" way of saying that others were applying it to him in both of these instances. Whatever the reason he chose to describe himself in these terms is less important that the revelation that he unwittingly calls upon a known concept to stand alone as a descriptor for his condition at the time.

It is significant then, not for its frequent use in the interview, but because it reveals that he understands what the term means in a larger intersubjective reality. This is also true in the instances where Connie assesses the actions of a brutal murderer or Karen assesses the behaviors of people using ABC programs. It is significant that this pattern is seen only at the point of intersection between private and public "troubles." This supports the idea that the dominant relevance structure of the social stock of knowledge is unwit-

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tingly perceived even when consciously denied. It also lends credence to the idea that the practical experience of "mental illness" changes over time, and changes less quickly than internalized notions of the concept, which are more firmly bound to relevance structures of the social stock of knowledge.

The possibility of changing the practical experience of "mental illness" occurred for several people in this sample after they connected in a meaningful way to the Alternatives By Consumers' community. We see in the next section that the type of initial contact with ABC has an enduring effect on their subsequent level of connection.

Initial Connection to ABC

In this section, I detail how mental health consumers became aware of the Alternatives By Consumers organization. In the thumbnail sketches of research participants that follow, I note whether they were referred to ABC by a provider (e.g., a case manager/therapist, hospital staff), and/or by peers in the mental health system. I also characterize their level of connection to the organization, "high," "moderate," "low." These patterns of involvement were determined by assessing: length of contact with the organization; formal position within ABC (e.g., staff, Board of Directors' member); volunteer activity for the organization, noting number of volunteer hours worked in an average week, and the kinds of tasks pursued, on or off-site; number of weekly visits to ABC and

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activities pursued during visits; participation in social events at ABC (parties, holiday meals, support meetings); participation in advocacy events (ABC-related presentations made in community or other forum); submission of material to ABC newsletter; and expressed commitment to the ideals of the organization (as participants defined them). Type of first contact and patterns of involvement contribute to the quality of relationships formed with other ABC participants and the embrace or rejection of ABC as a community. In their turn, these factors affect changes in self-identity within the ABC community.

Research Sample: ABC First Contact Sketches

Karen York first met Steven Ashton when they were in an outpatient Community Mental Health program together (i.e., "Charter House") in the late 1970s. Steven's comments to Karen about problems in the mental health system resonated with her. She subsequently left the CMH program to work as a volunteer with Steven. Her contact with Steven and the nascent ABC organization was through the peer network in the public mental health system.

Karen states that she has "learned a great deal" about mental health consumers and the difficulties they face living in community settings from Steven. In the time she has been with him, her status in the organization has gone from full-time volunteer (for several years) to paid Director of the ABC drop-in. She was Steven's first choice for the position when funds for the drop-in were received in 1985. Karen's degree of inv

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involvement with ABC is best characterized as unfailingly high for 8 years.

Jeff Bell was an early supporter of Steven Ashton and the work Steven sought to accomplish through the ABC organization. He has a long history with Steven Ashton, whom he met at a restaurant frequented by mental health consumers, when Steven was first organizing ABC. He connected with Steven because "he wanted to watch what would happen" as Steven pursued advocacy activities in the city. Jeff subsequently became involved in the work of the organization as well. His network linkage to ABC is clearly peer-based.

Although Jeff states that "I'm officially listed as a volunteer," during his interview, he also says "No, I'm not really a volunteer." He has helped out with various tasks, but has not volunteered to accompany consumers to review hearings, nor help find resources for people requesting them in the same ways that other volunteers have, using these criteria to define "official" volunteers. (Despite his protestations, he is recognized and appreciated by ABC staff as a valuable, if intermittent, volunteer.) He respects Ashton's work with the group a great deal and regrets Ashton does not have more power, although he notes the interstate reputation Ashton has achieved since they met in 1979. Since that time, the progression of his involvement with ABC is best characterized as declining from a formerly high level (for three years during the late 1970s and early 1980s) to a current moderate level (for five years, during the mid- to late 1980s).

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Sarah James' first contact with ABC came after her initial psychiatric hospitalization in 1981. Another resident in her boarding house told Sarah about ABC after her discharge, and she "immediately contacted them" by phone. When she was invited by a volunteer to come in and visit that same day, she did. Like other consumers in the sample, ABC provided opportunity for her to get out of her house and "do something." Her network linkage to the organization was (mental health consumer) peer-based.

Sarah was uncomfortable in the ABC setting at first, but when she was asked to help out and answer phones during her early exposure to the group, her fear at the assignment gave way to a feeling of acceptance. She interpreted the request as a communication of belief in her competence from other ABC participants, notably Karen York (who later became ABC's drop-in Director). She is a staunch supporter of the ABC philosophy and its work in the community. She is a volunteer of long-standing and also works part-time for pay, cleaning at the ABC center. Despite minor tiffs with staff and/or volunteers that caused her to end contact with the group for brief periods of time, her degree of involvement with ABC is best characterized as high during the last 6 years.

Carly Willis' first contact with Alternatives By Consumers followed her first psychiatric hospitalization in 1982. The network that brought her to ABC was peer-based. She was introduced to Steven Ashton through a friend she made in the hospital who did babysitting for Steven's family. Carly's friend encouraged her to call Steven during an emotional

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friend encouraged her to call Steven during an emotional crisis Carly experienced after her hospitalization.

Although she works full-time as a health professional, she has been an active member of ABC, and has been on their consumer Board of Directors since 1982. In addition to her participation as Board member, she has also worked as a volunteer for the organization. Her first introduction to ABC was mediated by direct contact with Steven Ashton, who "saved her life" (following a suicide attempt) and taught her a great deal as he helped her challenge a hospital commitment levied against her. When she learned of the organization Steven founded, she began volunteer work for it. She looks forward to the day when Ashton has more political clout to pursue aims of ABC, perhaps as an elected senator! Her degree of involvement can be characterized as falling from high for three years, to moderate for the last three years.

Dana Monroe first learned of ABC through a friend she made during a psychiatric hospitalization. The friend, Carly Willis, was a member of the ABC Board of Directors and encouraged Dana to visit ABC after her discharge. The network that connected Dana to ABC is clearly peer-based.

Dana was drawn to the group because she "felt supported," and kept in contact with it since that first contact in 1982. Over time, her involvement progressed to the point where she was working nearly full-time as a volunteer for the ABC newsletter (editing and illustrating articles) and Help Project (answering phones, helping people locate resources, etc.). When I was on medical leave from ABC employment for back surgery in 1986, Dana was called upon to help out with clerical needs in my absence. Exceptionally bright, she learned to use the computer word processor and data-base programs in my absence. By the time I returned (6 weeks later), she had become invaluable to the OUR Project and was hired on a part-time basis. When the budget was revised in October 1987, this allowed Steven to hire her for a full-time position. Her degree of involvement with ABC is best characterized as high for the past five years.

Suzanne Turner's first contact with ABC resulted from information she received about the organization from a resident of a group home for people labeled "mentally ill" where she was employed. Although Suzanne is a private mental health system consumer, her employment in facilities run by the public system provided the peer-based network link to ABC.

Suzanne was distressed that the owner of the home would not allow her to visit the residents after her employment was terminated. She called ABC in 1983 to find out if they could help her obtain permission to visit the residents and spoke with Steven Ashton. When she met Steven, she was drawn to him immediately because he "validated" her own feelings about the particular situation she faced. As she learned more about the work of ABC and Ashton's philosophy of "gentle justice," her participation increased. She worked as a volunteer for the Help Project for five months before becoming its paid director in late 1984. The degree of her involvement in the last five years is best characterized as a progression, from moderate during 1983, as she learned about the group, to high from 1984-1988, as she embraced their work.

Alice Wetherby first learned of ABC in 1982 when she attended a picnic sponsored by local Community Mental Health agencies in which ABC participated. The intensity of her involvement increased when a friend in the mental health system became more involved and asked Alice to come with her to ABC. Although the initial contact was through intersection of ABC's orbit with the orbit of other Community Mental Health Board agencies, Alice did not connect with the organization in a meaningful way until her peer in the mental health system encouraged her to do so.

The height of Alice's volunteer involvement came in 1986, when she worked nearly full-time on the ABC newsletter as editor and illustrator. In April 1987, Steven Ashton recruited her for the paid position of Help Project director, which she accepted. At the time of the interview, Alice had been working full-time in this capacity for five months. Her degree of involvement with ABC is best characterized by a progression, from low in 1982 to high from 1986 to 1987.

Connie Hawks first became aware of ABC in 1986 when she was a resident in one of the city's group homes for adults labeled "mentally ill." Another resident had mentioned the organization to her and asked if she wanted to visit the ABC center with him. The network linkage that brought her to ABC is clearly peer-based.

Although frightened of the new situation, Connie visited the center. The positive reception accorded her, even when she was manifesting emotional problems, drew her back to the group after her first contact. She, like others in the sample, has broken off contact with ABC after altercations with other volunteers and/or staff, but returns to the group nonetheless. At times, she has been a full-time (5 day/week) volunteer for the Help Project and is approving of the work of the organization. Despite the occasional lapses in ABC contact, her degree of involvement with the group is best characterized as high during the past two years.

Samantha Barker first learned of ABC through a friend working at the organization, in 1986. Knowing Samantha's interest in consumer-related issues, the friend encouraged Samantha's involvement with ABC. Thus, her linkage to the organization was through a peer-based network.

The philosophy of the group and its work in the community appealed to Samantha. Feeling she wanted to "give my talent or a gift to ABC," she volunteered her help on-site at ABC for a few months by washing hair, giving hair cuts, and engaging consumers in one-on-one conversation about personal hygiene. Much of her volunteer help has been off-site, however, securing donations of clothing to give to ABC patrons and assisting with the OUR Project video production. Samantha's degree of involvement is best characterized as moderate from 1986-1988.

Bill Peters' first contact with ABC occurred as a result of his friendship with a woman who was very involved with the organization during the mid-1980s. Like several people in this sample, the network linkage that brought Bill to ABC was peer-based.

In 1987, Bill began to come to the ABC drop-in center on a "fairly regular" basis, 2-3 times each week. He has been an on-again, off-again volunteer for the Help Project, but occasionally invests a great deal of time, helping with special projects like securing donations of food from area grocers for ABC's Thanksgiving Day meal. His degree of involvement in the year that he has been coming to ABC is best characterized as "moderate."

Sally Tisdale learned of ABC from an ABC volunteer she met while she was at the outpatient therapy clinic for people in public mental health, Community Support Systems (CSS). While ABC's work orbit frequently intersects with CSS (through referrals from CSS to ABC or through advocacy efforts by ABC on behalf of CSS clients), it was through personal contact with the ABC volunteer that Sally's interest in ABC was kindled. Her network linkage to the group was peer-based.

After the volunteer told her about ABC, she decided to visit the center, since she was seeking an alternative to traditional treatment at the time. Although it was clear to her that ABC did not offer treatment that would replace her current treatment regime (psychotherapy and major psychiatric medications), she kept coming to ABC "because there are few organizations anywhere that you can go and sit down and be friendly and be of use to somebody with a conversation...It helped me some, too" (Sally Tisdale 1987). At the time of the interview, she had been coming to ABC several times each week for about a year, occasionally acting as a volunteer for the drop-in center or Help Project (answering phones, problem-solving with patrons). Her degree of involvement can be characterized as moderate for the past year.

Martha Wright learned of ABC from a Community Support Systems (CSS) therapist. The therapist arranged for an ABC advocate to accompany Martha when she applied for disability benefits following a psychiatric hospitalization. Networking between CSS therapists and ABC becomes apparent through Martha's introduction to the organization.

In the ensuing year, Martha has visited the ABC center sporadically. However, about a month prior to the interview, she began to volunteer at the drop-in for four hours each day after a consumer peer in her "manic-depressive" support group encouraged her to do so. Her volunteer work "gets her out of her house" and gives her "something to do." She feels like she's "doing some good with the guys" at ABC. Her degree of involvement with ABC has gone from low for most of the past year to high in the past month; at the time of the interview this progression is best summarized by moderate involvement.

Pamela Martin first learned of ABC through staff at "Charter House" (a Community Mental Health Board agency, which provides an employment training program). When she also learned that Karen York was working at ABC as the drop-in director, this piqued her curiosity about the organization. Pamela and Karen had lived close to one another in childhood, and had kept in touch through the years. Intrigued by the frequent mention of ABC at Charter House by staff and some of her peers in the program there (which Pamela attends daily), Pamela called Karen to learn more about ABC. The network that connected Pamela to ABC was first through staff at Charter House, then from peers there. Another component was her friendship link to Karen.

When the drop-in center opened in June of 1985, Pamela began to stop in on occasion, but her own treatment schedule required that she attend programs with hours of operation similar to ABC's, preventing deeper involvement. She was able to attend the drop-in for five days consecutively during one brief period, however. She likes to come to the drop-in on Saturday's, but not when Karen isn't working.[1] She worries that ABC's Saturday staff, other than Karen, will not be able to control some of the people whose behavior makes her uncomfortable. She trusts Karen's competence in this area and enjoys her visits the most when Karen is there. Her degree of involvement from 1985 to 1987 is best characterized as low.

Ben Harris' first contact with ABC came as a referral from Night Care where he stayed following a psychiatric hospitalization until he could locate housing. He was told that ABC could help him find housing and could also help him move his belongings when the time arrived. Thus, the network linkage between Ben and ABC was the orbit of Community Mental Health (CMH) Board agencies with which ABC intersects (via the refer-

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[1] The full-time drop-in director is frequently given Saturday as time off, and other (approved by Ashton) ABC volunteers or staff supervise the center in her stead. No other ABC program (i.e., OUR Project or Help Project) operates on Saturday's.

ral provision in their contract with CMH).

Ben was disappointed by the slight help ABC offered at the time he needed to move, but believes that ABC does fulfill certain social needs for consumers through the drop-in program. He has not volunteered for ABC, but visits the center once or twice a week, as he has since his first contact with ABC in 1986. His involvement is best characterized as low for this 2 year period.

Summary First Contact Patterns with ABC

A summary of these "first ABC contact" patterns suggests that peer intervention is the primary medium for increasing consumers' involvement with the Alternatives By Consumers organization. This intervention usually consists of encouragement to come to the organization (i.e., the only mode of first contact for 71%, or ten of the fourteen consumers noted above). At the peer-only organization, the encouragement to become further involved is nurtured (as we see in the next section).

Looking at these patterns in relation to the first position at ABC assumed by newly introduced consumers and contrasting these to later positions assumed at ABC, we find a distinct effect of peer-referrals and/or of later "peer intervention," i.e., encouragement to become further involved. Of the ten people referred to ABC only by consumer peers, one person assumed a position on the Board of Directors (Carly); five people became "regular volunteers," helping out 3-5 times each week (Dana, Sarah, Karen, Suzanne, and Connie); and four people became "cyclical" and/or "off-site volunteers" (Jeff, Samantha, Bill, and Sally). Four other people whose referrals to ABC were either directly involved with providers (i.e., Ben from Night Care and Martha from Community Support Systems) or indirectly involved with providers (i.e., Alice whose first contact occurred during a Community Mental Health inter-agency picnic which ABC attended, and Pamela who was encouraged to contact ABC first by staff "Charter House") can be categorized as ABC "guests" during their early involvement.

What is also noteworthy in these patterns is the effect of peer referrals and/or peer intervention over time. Of the ten people referred by peers alone, the one member of the Board of Directors remained on the Board (Carly); two "regular volunteers" remain at that level of involvement (Sarah, Connie) and three others later became staff members (Dana, Karen, Suzanne); and the four "cyclical" or "off-site volunteers" have remained at that level of involvement. Following "peer intervention" two of the original four "guests" became regular volunteers or staff members (Alice and Martha); "guests" who were not specifically encouraged to become further involved by their mental health system peers did not do so (Ben and Pamela). Pamela's situation is different from Ben's, however. Her daily attendance at "Charter House" impedes further involvement despite her expressed desire to do so, and her friendship link with Karen is not the same as being encouraged to come to ABC by peers who find benefit by regularly coming to the ABC Center. These findings are arrayed in Figure 1, below.

Figure 1: ABC First Contact Sources and Connection to ABC

First position at ABC	First Referral Source	Intervention Source	Later position at ABC
Staff & Board of Directors	Peers Only	N/A	Same category
Regular volunteers	Peers Only	N/A	Same category or staff & Board
Cyclical or off-site volunteers	Peers Only	N/A	Same category
Guests	Provider involved referral	N/A	Same category
Guests	Provider involved referral	Peers	Regular volunteers or staff

It is significant that people whose contact with Alternatives By Consumers was a result of peer communications and/or peer intervention are consumers who progressed to or maintained a high level of involvement with the organization. Moderate levels of involvement are also related to peers-only contact sources: consumers either maintain that level of initial involvement or fall to that level of involvement after a period of more intense involvement. All persons once at a high level of involvement maintain at least a moderate level of connection with ABC. Other consumers, whose ABC contact source was through referral by a Community Mental Health Board agency, maintain a low level of ABC involvement unless peers intervene. This suggests that there may be an important interactive effect with peer referrals and likelihood of high involvement with consumer-run programs. It is a finding that indicates a fruitful area for additional research.

Why Consumers Become Involved: Feeling Accepted at ABC

To examine the relationship between current level of involvement and the experience of consumers at ABC, one theme that emerged from interview data analysis is important: most consumers felt supported and accepted by their peers at ABC. The effect of being in a gathering place where only consumers were in attendance was important for several people. Connie epitomizes this finding in the excerpt below.

> I feel that ... I can be [at ABC] and [be] secure and not ... be leery [about]: 'oh, what's gonna happen if I start hearing voices? What's gonna happen if I'm really upset or agitated? I gotta go there but I don't know how to deal with this.' It's ... your peers that are going there, and I can be myself and not expect to be perfect. ... I feel okay just making silly jokes. And ... people laugh at my jokes. You know, you don't have to be this famous joker... (Connie Hawks 1988).

Connie connects relief from worry about manifesting emotional difficulties to the presence of only peers at ABC. But the benefits of a peer-only atmosphere go beyond this. Being in the company of her peers frees her from the press of expectations from others. Connie is secure in her situated freedom at the ABC Center: she can be the person she knows herself to be.

Sarah expresses similar sentiments, connecting her comfort to a lack of fear at ABC.

> ... (crying) I hate to be around people sometimes, but I feel so comfortable at ABC because they know me ... and I don't have to be afraid (Sarah James 1987).

The fear disappears for Sarah at ABC because she is known. The acceptance she feels is holistic: she will not be judged for her fears or behaviors. Like Connie, Sarah experiences a situated freedom at the ABC Center. She feels her authentic self is recognized and accepted.

Alice realized a sense of purpose and acceptance at ABC when she first volunteered to work on the newsletter, seen in the following passage.

> Q: Did [feeling like you had a purpose at ABC] have something to do with working on the newsletter?
> R: It did have something to do with working on the newsletter. After I got started doing it. But it was also that people weren't turning away because I was having problems. They were giving to me when I was having problems ... being there for me (Alice Wetherby 1987)

Alice, too, felt a sense of acceptance despite manifestations of "problems." She was not rejected nor judged by others during her "problems," rather, she was included and given attention during those times. This infused her experiences at ABC with meaning that went beyond the purpose she felt realized by work on the newsletter. This realization may have provided impetus for her greater involvement with the organization.

Consumers with moderate involvement in the organization also recognized the pervading sense of acceptance and its importance to mental health care consumers. In the following passage, Samantha reflects on the importance of ABC:

> Well just existing, being there, knowing that ... whatever state of mind the consumer might be in, they can come in

> there and get some kind of assistance ... I think that the vast majority of the people I know there, it could have been the only link to support or assistance. The only link ... they didn't have the family or an institution, a friend in the institution, whether it be staff or patient, to get any support, stability out of. Knowing that they can count on ABC, you're open every day, what hours you're open, and they can go in there and socialize or they can go in there and sit in a corner (Samantha Barker 1987).

Samantha characterizes consumers' link to ABC as the only access many may have to some kind of security in their lives. They can count on receipt of support on a routine basis, regardless of their "state of mind" or whatever activities they chose--or chose not--to pursue at the center. For consumers bereft of support from "family or institutions," people at the ABC center offer assistance and non-judgmental acceptance to their peers.

In the next passage, Martha also reflects on the importance of a gathering place that is consumers only. She expresses insight into the effect of non-hierarchical relationships that characterize interaction patterns at ABC.

> I definitely feel more comfortable with consumers. I think that hierarchy of someone that is in a position, like CSS telling me that I can't go back to school ... that I won't be able to work a full-time job ... is all ... this stuff ... Here you're important no matter who you are, and Karen makes sure of that (Martha Wright 1987).

When Martha states that "Karen makes sure" you feel important at the ABC drop-in program, she illuminates the difference between ABC and other Community Mental Health services available to consumers. At the Community Support Systems (CSS) program, mental health professionals tell her she is incapable; at ABC she is told she is valued for herself, whatever capabilities she may or may not have. This instance reveals how definitions of self begin to change through involvement with ABC. It is plausible that Martha's realization that all are accepted at ABC contributed an impetus to become increasingly involved with the organization.

Even individuals who have low levels of involvement with ABC find worth in the consumer-run aspect of the organization. In the passage below, Ben suggests that the shared consumer status affects the kind of understanding that ABC staff manifest in relations with guests to the center.

> Q: What would you say is the best thing about ABC?
> R: Its social opportunity ... staff that can understand where you're coming from ... [because] they were all mental health patients at one time ... many of the things they do here, they do well considering. But that's not saying it's really good (Ben Harris 1987).

Ben was one of the least appreciative of ABC's work in the sample. Despite this general feeling, he sees that there is value in having staff available who "understand where he's coming from." When staff understand, they can accept Ben for who he is, as he is. Thus, Ben communicates that he feels ABC staff do not judge him. While <u>he</u> judges the employees and the work of ABC, implying a lower standard or quality in their work (e.g., "they do well considering" ... and what they do is "not really good"), the social opportunities accorded by the atmosphere of acceptance are still the features he describes as the "best things" about the ABC organization.

Some consumers in the sample told me how they approached other consumers at ABC which exemplify the communication of acceptance referred to in this section. In the nature of interpersonal interaction typifying many of the relationships at ABC, we hear the message of non-judgmental support. We listen to these voices in the following section.

Interpersonal Interactions at ABC

Alternatives By Consumers is an organization that aspires to treat mental health consumers as "people first, and people with problems, second." This philosophy is not necessarily one that consumers bring to the organization when they first become involved and/or begin to volunteer their services to it. Karen, the drop-in Director, learned about the nature of people with problems from Steven Ashton. She reflects on these early lessons, which were sometimes difficult for her, below.

> Steven ... has really educated me so much. Like, it was new for me to ... see these people begging for cigarettes, begging for money and stuff, and Steven said: Karen, that's how a lot of them have learned to make it in those [mental] institutions ... I said: Steven, well do they ever pay those things back? ... Because ... I was really ... shook up at first, the way people used to talk to Steven. Maybe cuss him and stuff ... then the next day maybe they would call or come in and apologize. And I'm saying: these people [are] too wishy-washy for me. (laugh) ... then after Steven begin to explain it to me, some of the things, that happened to me before. Maybe I could accept them better and I ... get a little mad at it. But I wouldn't [stay mad], because I knew they'd be back to apologize... (Karen York 1987).

From Steven, Karen learned several vital pieces of information. Some of the behaviors (e.g., begging money or cigarettes) she observed among consumers were survival skills learned in long-term care institutions. Other behaviors (e.g., cussing at Steven) while disturbing, were transitory; liable to be regretted later; and nearly always followed by gestures of reparation. This knowledge persuaded Karen to alter her judgment of these consumers as "too wishy-washy" for her to tolerate. She also reflects on previous experiences in light of the new knowledge and "accepts them better." Importantly, she models her own behavior after Steven's, and learns to temper her anger at some behaviors. She learns to expect that consumers will make amends for behavioral transgressions.

In this exchange of experiential knowledge, Karen alters her definition of self (i.e., she is a person who can now tolerate "wishy-washy" behaviors) and the definition of the situation she applies to others is changed as well. The need to make judgments about other consumers decreases.

Some consumers do not require tutelage from Steven, as Karen did, to learn how best to offer support to peers, but can apply their own knowledge, borne of experience with emotional travail, to problematic situations. In the following passage, Sarah describes a typical interaction with peers who are manifesting obvious signs of distress (e.g., fear of others, fear of things that appear changed when they aren't, fear of things unseen or unheard by others). Sarah's own experiences teach her how to relate to others in similar straits.

> You know what I say to people? It's real to you isn't it? And it hurts so much, doesn't it? I said: but it's really not. You, I'm sure, think "it's real, it is affecting me" but it is part of the illness, it's not real. That's what I tell people. I don't tell them: well, that's ridiculous. Because it's not ridiculous cause I've been there (Sarah James 1987).

Sarah's approach to understanding her peers depends on ins

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insight similar to what Steven shared with Karen, i.e., behaviors must be seen in their context. When the relativistic nature of problematic behaviors are understood, the need to judge the behavior dissolves. It is noteworthy that Sarah relies on a conception of the problems as "part of the illness" she deems to be external to the person. Thus, consumers are not responsible for the manifestations they present. The person in turmoil requires empathy, not judgment.

These examples demonstrate the application of experiential knowledge to interactions with consumers using the ABC organization, albeit from different sources (i.e., Karen's was indirect, mediated by Steven's insightful observations; Sarah's was direct, a result of insight through experience). In the following section, we examine the next stage in the progressive evolution of ABC relationships: the development of reciprocity.

Development of Reciprocal Relationships

Another characteristic trait of interactions at ABC was reciprocity. Staff and volunteers were not only sources of support to people using ABC programs; they, too, were recipients of support from people they assisted. The following interview excerpt exemplifies the reciprocal nature of support achieved in ongoing interaction. Suzanne Turner, past Director of the Help Project, reflects on the support she realized when she was assisting one man for several months.

> [A consumer at ABC] and I had a really neat relationship ... at some level, I felt a connection ... a pull or something ... and it ... was meaningful. He got something from me, and I never knew what it was. ... He was willing to trust me and ... talk to me and I felt he could see something in me that I didn't even see ... he pulled a piece of myself out of me that I never [knew was there] ... and ... he would reorient me to why I was there. Without even trying. Sometimes when I'd get burned out, he would ... be able to recharge me...And he gave me something back. [It was] more than just the reward of doing something, but emotionally ... he poured a lot of acceptance on me. ... He had a lot of unconditional love for me ...that comes from who knows where, but it's [there] (Suzanne Turner 1988).

The ineffable quality of what was exchanged in the relationship between this consumer and Suzanne did not prevent her from knowing it held meaning. The relationship permitted a continuing definition of her ABC work situation as something that mattered. His outpouring of acceptance, whose source is a mystery given her knowledge (communicated to me during her interview) of the pain and trauma of his past (e.g., severe tardive dyskinesia, the recent suicide of a loved woman-friend, problems with alcoholism, rejection by family, friends and system providers), allowed her insight into the human capacity for caring. In this interaction, she learns to redefine what she "knew" about mental health consumers (e.g., victims of their past). Her enlarged vision sees consumers as people who are capable of offering "unconditional love."

Suzanne was not the only consumer in the sample who saw the capacity for "unconditional love" among consumers patronizing the center. Carly Willis noted this as well, when asked to describe the relationships she developed at ABC.

> I found out what unconditional love is by coming here. That's probably the ... most memorable or most remarkable thing about [ABC] ...You have a group of people who have nothing and who constantly give to other people. They have no material possessions at all ... A lot of them are in and out of ... craziness, yet they would never hesitate to give to somebody else who was in pain or needed something (Carly Willis 1987).

Carly, too, learns about unconditional love from people "in and out of craziness" through her contact with ABC. They do not have things to give, so they give of themselves. In an atmosphere of support and acceptance, consumers learn they have much to offer each other. Incrementally, they develop capacities to offer and accept love.

Although Alice does not use the language of "unconditional love," her reflections on support received from those she assisted during her tenure as Help Project Director enrich an understanding of the evolutionary nature of relationships between consumers at ABC. The notion of developing reciprocity is clearly seen in the following passage.

> There's another pay here that's ... actually more fulfilling ... than the [salary]. ... Like when ... you're kind of preaching at someone ... 'knock this off, do this, knock this off, do this,' constantly ... and then you give them some advice and they reach out and shake your hand. ... That there is payment.... Or when I help someone ... go to a social security [disability benefit] review ... and then my review comes up and that person comes back to me and says: ... 'do you need to talk to someone? Do ... you need to be with be with someone? ... Can I take you out to coffee?' Those things are pay, too ... seeing people's faces and seeing them doing well, and hearing feed-back about it. That's a good thing about this place. ...Most [of] the people here will ... give of themselves when they can (Alice Wetherby 1987).

Alice highlights several important features of ABC interactions: reciprocity develops despite patrons' experience of verbal sanctions about behaviors; consumer staff and consumer patrons sometimes confront similar situations in the system; the shared experiential base facilitates exchange of empathy; there is reward in helping others; and there is reward in learning that the help offered has been beneficial. Alice also lends credence to the report of others: a characteristic trait for ABC participants is their willingness to "give of themselves when they can."

It is through the vehicle of reciprocal relationships that the next evolutionary stage of consumers' alteration of their definition of self is attained. We turn next to examine the changes in identity people in the sample report as an outgrowth of their involvement with ABC.

Changed Definitions of Self and ABC Involvement

People who have been involved with ABC the longest can reflect on their early experiences in the organization and relate it to changes in their perception of self. Karen does this in the following passage, and connects her observations of other consumers to a desire not to be "like that." ABC provided the vehicle for realizing this desire.

> I see other people ... that were medicated or whatever, and... I had to say: I don't want to be like that. Many ... times I used to go home and cry ...because I was thinking ... it would change. But I think what really changed was when I started working at ABC, because I've always liked to help people and ... being able to help people and get out and work with them and ... just working with people that were like you ... There was people who really appreciated these things... and... this really made you feel good (Karen York 1987).

This is an important passage, for it reveals that Karen's desire to change was not sufficient to impel a change. Neither did the passage of time alter her circumstance. It was only after she began to work with ABC as a volunteer, helping peers who appreciated her efforts, that her self-esteem was enhanced.

Karen's volunteer work during ABC's early years provided an important model for others to follow. In Sarah's reflection below, we find that Karen's encouragement was a vital component in Sarah's participation in the work of ABC.

> Steven was gone most of the time, and I really started [working at ABC because of Karen]. The ... other phone line rang when Karen was on the phone, and I just mouthed, want me to get it? And she goes: yeah, do you know how to do phones? ... I think that was before ... I would tell them anything about me. It was like I'm gonna protect what little is left here. You're not getting any of it. And I picked up the phone, that's how it started. And then that's how Karen and I got talking. I felt important again (Sarah James 1987).

Sarah communicates the atmosphere at ABC during its early years. Steven was out of the office a great deal, involved with advocacy efforts off-site. Karen, a full-time volunteer, provided guidance to other consumers wanting to volunteer and/or simply visit. Until the day Karen asked Sarah to answer phones, Sarah might have been classified as a "guest only." In that instance, Sarah became "one who could help," and subsequently, "one who could share," i.e., talk to Karen and embrace the honest disclosure ethos of the organization. It was significant to Sarah that she was asked to help (and assumed competent to do so) before others "knew anything about" her (e.g., her previous 11 year work history). When Karen made her "feel important again," Sarah could lower her guard and participate in conversation more freely.

It is important in the context of ABC-related changes in self perception to recall the importance of the temporal element. Sarah felt "important again," but it was a feeling subject to fluctuations. When Sarah speaks of other early experiences, she communicates the on-going need for acknowledgment from others. She learns of her need to temper the pace of her volunteer work.

> Q: You mean part of the hospitalizations were due to your involvement in ABC?
> R: [Only] ... because I was so involved. There's so much need ... And I wanted to do it. I felt good. I could do it. I would do it. And whew, I just went down ...
> Q: What? You were doing too much?
> R: Uh huh. So busy I didn't even notice the signs ... There were several times where very poor management [affected me]. This was way before, we had additional people. Steven was overloaded. We needed volunteers. And I would be out and out verbally harassed [or ignored] and ... [if I] got up to move, [I would] lose [my] chair ... [I was] working there for three or four hours. Hours! [For months in a row.] Organizing this, that.... It hurt cause I thought I was appreciated ... and I found out I wasn't. It's hard to say why I came back ... but I found out. ... Not only did I need ABC, ABC needed me. And I knew it. I could tell. Come in. No real filing system, no organization. A mess. ... Well, ... I knew at that point I was missed (Sarah James 1987).

During times of emotional travail, the need for support is high. Verbal harassment, being ignored, and losing her space in the small office where she pursued organizing activities contributed to a decline in Sarah's feeling of early importance to ABC. When the only thing that seemed worthwhile at the time turned sour in these ways, Sarah agreed to be rehospitalized. Without acknowledgment, she could not maintain her high level of involvement.

When she returned to ABC following hospitalization, she could see that her work had mattered to the organization. She could recapture the feeling of importance and worth. Sarah comes to describe her relationship to ABC as a "marriage."

> It's like being married. You have this problem that you don't know what to do with it but you do your best, and often times you get frustrated. So, a lot of times ... I'll divorce ABC. For self-preservation. But I keep waiting for someone to call me or come by and say: we miss you. And it's never happened ... I feel very close to, and I believe in, what ABC is doing. That's why I am able to do what I do (Sarah James 1987).

Sarah's ability to tolerate time periods when she "divorces ABC" without appeals to return because she is missed, speaks of her lessened need for unrelenting support and acknowledgment. Over time, her allegiance to organizational ideals has increased. Her identity as "consumer advocate" is evolving.

Connie also credits ABC participation as a means to "feeling good." In the following passage, she credits her advocacy work at ABC as a worthy endeavor that affected her sense of self.

> I started volunteering there, and I felt ... my confidence ... going up, and I slowly advocated for people, which really made me feel good. I was giving to people, so ... I wasn't so wrapped up in myself ...A lot of times I've forgotten about my problems, my everyday problems and stuff that I dealt with, all day. (laugh) And just at night or in the evening [I'd remember them]. It built up a lot of my confidence. It was a good experience volunteering [regularly] (Connie Hawks 1988).

Connie's advocacy for other consumers lessens her usual introspection, and provides a foundation of confidence for her. Her comments also indicate an awareness of the time dimension in these changes: confidence builds gradually and advocacy efforts are slowly undertaken. It has taken Connie two years of high involvement with ABC to be able to mark these changes in herself.

Alice also reveals an evolutionary progression in her sense of self that she connects to participation in ABC. In the passage below, Alice reflects on the effect ABC had on her struggle to determine "who she is."

> I was involved more with ABC [during] my last hospitalization, and I started realizing more about who I was and about how much work I had to do for me to know who I was. ... I didn't have an identity of Alice Wetherby. My identity was other people.... I started realizing that, and that ABC was giving me a little room to be who I was. To be who I am, and give me some things to see that (Alice Wetherby 1987).

Alice's growing involvement with ABC affected issues she worked on while hospitalized, several months prior to recruitment for an ABC staff position. She saw that her identity as a unique person was emerging as she worked at ABC.

Alice also gives voice to the temporal dimension that is important in ABC involvement. The evolution in Sarah's definition of self occurred over a number of years. Connie's has begun after two years. When I interviewed with Alice, her high level of involvement had been on-going for only one year. In the following passage, it is easy to discern she has not yet achieved a level of comfort with her "emergent self."

> What's scaring me lately is ... I'm not such a buried person, ... I'm walking on my own or with people. Not so much on my own, but with people, instead of behind them. ... It makes a difference. I've still got a lot to do, but that's what I'm running into lately ... self-identity issues, who I am ... (Alice Wetherby 1987).

Alice is scared by the changes she feels in her realm of "self-identity issues," which she hastens to qualify ("walking not so much on my own;""still got a lot to do;" still "running into" the issues). And yet, her experiences in the system impel her towards this large undertaking (i.e., changing her definition of self):

> All I know is that I can now do some things through ABC to help some of the things that I've seen that were wrong (Alice Wetherby 1987).

Alice has not yet mastered the issues that she sees as barriers to an altered perception of self, but she is clearly on her way. ABC participation has provided her with a vehicle moving her closer to a possible self-identity change: from "mental patient" to "consumer advocate."

Another significant finding in these interview data is that even persons with a low level of ABC involvement understand the potential for change that might be afforded by increased participation. Pamela exemplifies this trend in her comments below.

> I was solely coming here, like, five days a week on my own. It was like you were giving [me] a chance to branch out by myself ... to help myself (Pamela Martin 1987).

Pamela had one experience with being at ABC for a five day week. But the experience allowed her to perceive the possibilities of change. It was seen as an opportunity, a vehicle for growth. Given other consumers' experience with on-going ABC involvement, it is likely that more constant interaction with ABC consumers and advocacy work could affect Pamela as much as others report it has positively affected them.

The changed perceptions of self reviewed in this section have relied on a <u>proactive</u> vision of self, i.e., positive changes are noticed over time. In contrast, a few people in the sample mark their changes in self-identity by reacting to consumers who currently use ABC programs. Their comments are considered next.

The Backward Glance: 'Oh, How I've changed'

Despite nuances in approach, mental health consumers in this section define themselves as changed people by confronting visions of their past. In essence, they see who they are by seeing who they were.

When Carly "looks back," she sees the present day composition of guests at ABC through a veil of gratitude.

> I guess what attracts me, why I keep coming back, is it gives me gratitude. It shows me where I was, and takes me out of my self pity when I come back and see people that have it worse off than me (Carly Willis 1987).

Carly seems humbled by her experience with reflection, finding little excuse for self-pity when she compares herself to other people currently using the ABC center. The others seem to embody the 'ghost of Carly past,' and allow her clearer vision of her present self.

Jeff introduces his backward glance apologetically.

> Well, I hate to say this, it may ... come across as sadistic but, I love to come to the drop-in as a subtle reminder of what I used to be. And that, if I don't keep on the straight and narrow, I could become like that very easy. [I come] to look at somebody whose worse off than [me] ... and kind of reflect (Jeff Bell, 1987).

Like Carly, Jeff compares himself to others at ABC and knows how he has changed. His perception of current day patrons of ABC encourages him to remain free from substance abuse (i.e., the straight and narrow). Although he does not make it explicit, my assessment of his comments reflect another important dimension in Jeff's experiences in mental health care. He implies that this comparative look at others may provide impetus for his tenacious efforts to pursue psychotherapy (he has seen 27 different therapists). Jeff's backward glance serves to propel his efforts at self-change. He has not yet achieved a sense of self that is unerringly sound (e.g., "I could [still] become like that very easy"), but he can mark the self-change thus far attained by seeing his former self in others at ABC.

Other consumers in the sample also use the ABC population as an identity marker, but in a much different way. They use ABC consumers as a comparison point to illustrate who they aren't.

Distancing and Self-Identity at ABC

ABC participants who are heard below evoke a notion of social distance to communicate their perception of self. By telling me how unlike they are to others at ABC, they fend off images of self as mental health consumer (despite its applicability). They are dissimilar to consumers who learn to redefine themselves in positive ways through contact with the organization. There is a certain rigidity apparent in their views, and a tacit reliance on an image of "mental illness," and/or "mentally ill" people as sub-standard.

Samantha Barker looks at consumers at ABC and knows how "lucky" she is.

> Q: Why did you connect to ABC at all?
> R: 'Cause I felt real lucky ... that I'm not one of 'em. I have my own problems and weaknesses, but I haven't been as used and abused or permanently maimed from some of the

> abuses I've suffered as the people that I see using ... ABC. I feel so blessed ... I can go in there on a bad day and come out smiling. That is why I related to it (Samantha Barker 1987).

The unwitting disparagement of ABC consumers in Samantha's comments is realized in the phrase "I'm not one of 'em." She has ranked the group according to internal dimensions: extent of "use and abuse" suffered, and whether the degree experienced "permanently maimed" the individual. Her difference is conceptualized as "a blessing," or by virtue of chance. The source of her difference (and theirs) is not controlled by human intervention, it is instead due to God or luck. Nor is it mental health that sets her apart; it is fate. It is therefore unlikely that Samantha would become involved at a high level with the organization. It is equally unlikely that she would ever develop an image of self as "consumer advocate." We have heard from the consumers above that is belief in <u>each other</u> that alters their self-definition. In that alteration, they discover their mental health.

Ben reveals the foundation for his low degree of ABC involvement in the following passage. His scale of internal ranking of the group is simple: "regular" or "mentally ill." He evokes a negative image of "mental illness" less graphically than Samantha (i.e., "permanently maiming") but the social distance he creates between himself and "mentally ill people" is as great.

The following excerpt was Ben's summary statement of difficulties he experienced in relating to other consumers at ABC. These were variously attributed to consumers' "obnoxious, complaining behaviors," marked by talk of "conspiratorial garbage" and/or by "interjecting a bunch of garbage" during his attempts to have "some kind of an intelligent conversation" with another person at the ABC drop-in (Ben Harris 1987). He sees danger in consumer-to-consumer relationships.

> Now Karen's nice. Karen, you can talk to like a regular person. So that's why, you know, if you get too much into this or you get too comfortable with it, I think it can be dangerous (Ben Harris 1987).

Ben recognizes that Karen relates to him as a "regular person." He and Karen are "regular person" peers. He finds this potentially harmful. It was later in the interview that Ben revealed just what "danger" he thought was involved.

> If you put prisoners all in one place and all they hang around is other prisoners, they're gonna start thinking like prisoners and getting more destructive. ... ABC is like a prison. ... Let's get them thinking like human beings. All the [ABC center] does is reinforce mental illness. 'Cause all you ever do is talk to mentally ill people (Ben Harris 1987).

Delimiting the population at ABC (i.e., consumers only) is the danger. Ben juxtaposes the populations (prisoners and "mentally ill people") and suggests that neither population engages in "thinking like human beings." His comments imply that reinforcing "mental illness," is achieved by segregating consumers at the center and limiting conversational opportunities with other people who might "think like human beings," and/or relate in ways known to "regular persons." Neither of these descriptions ("regular persons" or "people who think like human beings") apply to the population of "mentally ill people" at ABC, but both apply to Ben (and perhaps to Karen).

Ben thus achieves great social distance by use of his yard stick, seeing harm in conversation between "mentally ill people" at ABC. He has constructed a situation where he is literally without peer at ABC.[1] Thus, he is unlikely to embrace a self-definition that includes "consumer advocate."

Ben presents paradoxical communications about ABC. His earlier comments suggested that he appreciated the "as is" ac ceptance of himself (and other consumers), particularly as manifested by staff at ABC. In the passage above, he disparages the population as a whole. This indicates another barrier to Ben's assumption of a "consumer advocate" identity. Although he appreciates non-judgmental acceptance of his own consumer status, he cannot offer non-judgmental acceptance to other consumers. He wishes no identification with the population of consumers, but allows that being understood as a consumer is a positive feature at ABC. In this self-definition as "a peer apart," Ben will be unlikely to embrace the organizational philosophy (i.e., through a medium of "gentle justice," consumers learn from each other). Unless these tensions in his approach to the group are resolved, Ben will remain unempowered through participation in Alternatives By Consumers.

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[1] Ben was one of several consumers in this research sample who mentioned disadvantages to the consumers-only feature of ABC, but all others mentioned it in context of limiting social opportunity and/or presenting difficulties when disparate social circles intersected (e.g., consumer friends with friends made at work situations, neighbors, families, etc.).

Conclusions

A significant finding in this research is that the pattern of first contact with the Alternatives By Consumers organization affects the degree of subsequent connection to the organization. "Peers only" and/or peer intervention after providers' referrals to ABC are likely to result in moderate or high levels of involvement with the organization. This likelihood is decreased when referrals to the organization are made solely by providers.

Patterns of first contact are related to subsequent abilities to appreciate the non-hierarchical (i.e., peers only) atmosphere of the ABC center. Feeling accepted despite manifestation of emotional problems provides meaning and purpose to participating consumers. Attention by staff and others acceded to consumers "having problems" may communicate "behavioral rules" to follow to achieve attention in a similar way to that found in the treatment chapter (Chapter 6).

In the hospital, harm to self guarantees attention. At Alternatives By Consumers, "having problems" may guarantee attention, but consumers need not use lethal means to garner it. This may lend support to Ben's claim that "ABC reinforces mental illness," in that attention is guaranteed by manifestation of "problems." It is less harmful to self, however, and the range of attention-getting options (e.g., work on the newsletter or advocacy with others) is greater than that allowed in hospital settings. In the absence of other social supports, the non-judgmental acceptance and assistance provided by ABC may be a vital link to maintaining community residence (and avoiding rehospitalization).

The communications about self received through interactions at ABC may alter insidious definitions of self received from mental health professionals and/or providers (e.g., Martha will be unable to work). An important element in this feature is the non-hierarchical atmosphere of the organization. This message of "self as capable" and "self as important," regardless of skill level or abilities may stimulate increased involvement with ABC.

Consumers apply experiential knowledge to their interactions with other consumers at the ABC center. This knowledge is either acquired through direct experience (as Sarah typifies), or learned through observation (as Steven demonstrated) and/or through communications about observations about the actual exigencies that impinge on consumers' existence (as Karen learned from Steven).

In the application of experiential knowledge, definitions of self and others are altered. Consumers are people who learn from each other (e.g., to tolerate certain behaviors) and they see each other in different ways (e.g., through relativistic interpretation of the context within which certain behaviors are manifested). The need to judge other consumers decreases with the application of this knowledge. Empathetic interactions characterize the application of this knowledge.

It should be recalled that (in Chapter 6, "Consumers' Treatment Experiences"), a significant finding was that hospital staff on the private floor exemplified empathy in interactions and that staff on the public floor eschewed it. Over time, consumers routinely subject to non-empathetic treatment by hospital staff on the public floor (through readmission) may also alter their definition of "helpers" and self in the ABC context. They are not perceived as "behavioral problems" at ABC, but as people with problems. Moreover, "helpers" may not be people who provide assistance <u>and</u> disparagement; "helpers" may be people who assist <u>and</u> respect the struggles mental health care consumers face. If such quality of help is available in the community, the need for rehospitalization to find it on the private floor (by chance, if assigned there), or receive it while also degraded on the public floor, may diminish or become extinguished.

It was found that some consumers experienced "unconditional love" from others at the organization. Another finding revealed that reciprocity in relationships develop over time if significant levels of involvement with ABC are maintained. This suggests that in time, consumers can and do learn to express "unconditional love" to others. Expressions of reciprocal caring was found even when consumers received verbal sanctions about their behaviors at ABC. As they internalize notions of their own acceptability in context of ABC interactions, they may also realize "unconditional love" for themselves.

It was also noted that empathy for others may be generated by shared situations (i.e., applicable to patrons and staff at ABC) in the system of care. Help to others in similar positions also was found to be related to increase in self-confidence and self-esteem, especially when positive acknowledgment of the help proffered was communicated.

Another significant finding was that the desire to change a troubling emotional circumstance was not a sufficient condition to achieve such change. Nor was the passage of time, in and of itself, sufficient to allow change to occur. Rather, investment of time and energies in the advocacy work of the organization provided the vehicle for such change to occur.

On-going support and acknowledgment of volunteer and/or staff work for the organization was found to be a crucial component in maintenance of high levels of involvement with ABC. Data suggest that this support may be especially important during a consumers' early foray into volunteer activities. Early support may also allow consumers to begin the process of honest disclosure, and realize that their authentic self is acceptable to others.

A related finding is that the proffer of support over time may enter consumers' consciousness as part of a "new" reality, i.e., "I am supported here." Once this is realized, the need for constant acknowledgment of worth or value in their work for the organization diminishes. This contributes to enlarging consumers' allegiance, beyond particular support persons at the organization to support of the organization's ideals. In this passage, the notion of self as consumer advocate emerges.

Another finding that illuminates a likely connection between diminished risk for psychiatric hospitalization and work for the organization is decreasing time devoted to brooding introspection by proactive advocacy with and for other consumers at ABC. It was noted in Chapter 6 that the problem of boredom in hospital settings tended to exacerbate troubling conditions that frequently impelled consumers to seek hospitalization (e.g., depression, self-harming impulses). Displacing boredom by advocacy work thus lessens opportunity to wallow in emotional mires.

Other findings highlight that the transition to "consumer advocate" from "mental patient" is dependent on abilities and/or willingness to accept the "new self" as it emerges over time. Fear about the change and unwitting or conscious disparagement of the consumer population suggest impediments to change requiring resolution before the "new" definition of self takes secure root. Consumers with a low level of involvement in ABC exhibit beginning awareness of self-change possibilities during periods of brief, but intensive, involvement (as Pamela did in one 5-day period).

Some consumers mark their passage to changed self-perception by the "backward glance," i.e., by observing how unlike their former selves they are when self-compared to other consumers using the ABC center. In contradistinction are consumers who offer self-comparisons between themselves and others at ABC as a way to create social distance. They rank the population according to internal dimensions (e.g., extent of previous abuse, manifestation of severe disability), and use these determinations to judge their peers (e.g., "regular persons" versus "mentally ill people" incapable of "thinking like human beings"). This tendency to eschew interaction with other consumers; manifest belief that change is not possible through human intervention; and render negative evaluations of other consumers conflates the likelihood that these consumers will neither become "consumer advocates," nor experience an empowerment (through alteration of self-image) by virtue of their current levels of moderate or low involvement with the organization. It is also unlikely that they will seek to become more involved with the organization.

Individuals who become "consumer advocates," as well as those who exhibit signs of transition (from "mental patient" to "consumer advocate" images of self), are consumers who have changed the definition of the situation that they received from mental health professionals and providers. They see each other, and gradually learn to see themselves, as people who have much to offer each other. They are acceptable, competent and valuable, as are their peers, whatever emotional circumstance they experience. *In this empowering embrace of an altered self-definition, they discover their mental health within the community* created by the advent of the Alternatives By Consumers organization.

In the context of these self-changes, consumers express an understanding of elements in contemporary mental health treatment that need revision. They also learn to see components of ABC involvement that advance or impede their recovery of mental health. In the next chapter, consumers give voice to ideas for system and organizational change.

CHAPTER 8

CONSUMERS' SUGGESTIONS FOR CHANGE

Introduction

This chapter focuses on "change issues" as they relate to the mental health care system. During the interviews for this research project, I encouraged consumers participating in the Alternatives By Consumers (ABC) organization who volunteered to be part of this research to explore issues of concern to them in their mental health care experiences. More specifically, I asked them to provide suggestions for altering conditions they had identified as troublesome in their own, and their peers', experiences. The change issues that emerged during interviewing are reflected in the topical areas of this chapter. These include issues related to: major psychiatric medications; psychotherapy; diagnosis; hospital admission; inpatient programs; hospital staff; alternatives to hospitalization; outpatient programs; vocational rehabilitation programs; provider-consumer relationships; professionals' education; consumers' education; basic needs; residential placements; system expansion; system operations; Alternative By Consumers' operations and change; and stigma. Most suggestions are clearly change-oriented; others suggest ways in which existing treatment opportunities might be more effectively used; still others look for eventual abolishment of certain treatments or conditions that have had negative impact on ABC consumers. However, no ABC participant in this research project suggested that the mental health system should be abolished.

Four general themes dominated interview data with respect to mental health consumers' ideas for changing the mental health system: need for changes in treatment; need for changes in system operations; need for changes in relationships (between providers, consumers, and the larger community); and need for an historical perspective on addressing the problems. Consumers' suggestions for system change were most detailed in treatment areas that had dominated their mental health care experiences. Ideas for changing operations at Alternatives By Consumers (ABC) are largely characterized by attention to volunteer issues and need for expansion of ABC operations.

I have grouped responses from research participants in clusters. Persons involved at high levels with the ABC organization, i.e., staff, Board of Directors members, and "regular volunteers" working 3-5 times per week at ABC routinely offered constructions of their self-identity during interviews as "consumer advocates" or by references which indicate they are "transitional advocates." This latter term is one I use to describe the apparent dynamic in their constructions of self: they are not yet comfortable with describing themselves solely as advocates, but their interview responses do not indicate they see themselves solely as "mental patients," either. Persons involved at moderate levels with the ABC organization, i.e., "cyclical" or "off-site" volunteers working less than 3-5 times per week are referred to by the single term, "cyclical volunteers." Persons currently connected to ABC activities at low levels of involvement, i.e., "guests," are referred to by that term. One other category for a response cluster is sometimes used, i.e., "others." Although persons who fall in this category may sometimes overlap with "cyclical volunteers" by virtue of their moderate level of involvement with ABC, their constructions of self-identity in interview responses do not reflect patterns found for "consumer advocates," or "transitional advocates." They do not reflect patterns that suggest identity is posed predominantly by a "mental patient" construction, either. Rather, their suggestions are more closely aligned with "guests" of ABC, and are sometimes clustered together with them.

The analytical distinctions between these five "ABC identity categories" (advocates, transitional advocates, cyclical volunteers, guests and others) are sometimes blurred. However, most of the time there is a characteristic type of response among persons who have learned to construct an image of self specific to the ABC community that corresponds to the category I use to describe them.

When there are apparent patterns in responses suggesting different degrees of involvement with ABC have affected change suggestions within a specific section, the section is subdivided into ABC identity categories: "consumer advocates' perspective;" "transitional advocates' perspective;" "cyclical volunteers' perspective;" and "guests'" and "others'" perspective." (I have paraphrased most of the suggestions to facilitate ready identification of similar patterns in their responses.) When patterns are not apparent, change suggestions for the section are reviewed as a whole.

The most significant difference between persons in the "consumer advocates" and/or "transitional advocates" categories; the "cyclical volunteers" category; and/or the "guests" and "others" categories was the degree to which people based ideas for change on belief that consumers will affect the care system or tacit rejection of this belief. Those persons more involved with Alternatives By Consumers <u>and</u> who present constructions of a changed or changing self-identity specific to the ABC community tended to recognize and acknowledge possibility of consumer-initiated change; those less involved tended to reject it.

We will examine representative suggestions for change offered by consumers in the following pages. The discussion will conclude by assessing "Trends in change suggestions" immediately following examination of change suggestions offered.

<u>Medication Issues</u>

"Consumer Advocates'" Perspective

"Consumer advocates" address the medication issue more broadly than consumers who are not as involved with the Alternatives By Consumers (ABC) organization. They understand that the use of medications is a dominant mode of treatment, but react to this critically, suggesting that something other than drug use benefit explains why so many consumers are prescribed high maintenance levels of drugs. Consumers' exploration of relevant issues and change suggestions for major psychiatric medication use follow.

Medication use is reinforced in the system. People are afraid to discontinue its use [having been frequently warned of their inability to function without it]. For consumers who want to discontinue use of medications, no ready support from others who have successfully discontinued medications is available. Consumers who may have done so are not known to others (Carly Willis 1987). It is apparently a very rare occurrence. Thus, the suggestion for change includes compilation of a list of consumers known to have discontinued use of medications willing to be "on tap" for support to others with similar interests.

The site of medication's greatest reinforcement is in the hospital. Its benefit (regardless of type of drug prescribed) is frequently misrepresented to consumers (e.g., "it will make you think straighter"). Taking medications as prescribed during an inpatient stay is also frequently a contingency of hospital discharge. It is not atypical for consumers who were overtly or covertly coerced into taking them while hospitalized to discontinue their use upon discharge (Connie Hawks 1987). These observations suggest that providing information to consumers about the drugs would allow them to provide informed consent. Were more information available, consumers who return to the community might make different decisions (e.g., abrupt versus gradual withdrawal) about terminating psychiatric drug use.

Another suggestion indicated a need for more medications' research which challenges customary use and assumptions upon which its use is founded (i.e., emotional problems are biochemical in nature and/or are genetically based). Moreover, it was noted that challenging contemporary usage of these drugs appears as a radical approach within the field. It is a complex and contentious issue: people who believe they benefit from the drugs' use cannot be discounted, and mandating psychotherapy as a replacement for the drugs might be as coercive as forcing medications on people (Suzanne Turner 1988). Additional research would allow greater attention to such issues, and might result in more reasoned administration of psychiatric drugs.

"Transitional Advocates'" Perspective

People at ABC who construct their primary social identity as "mental patient," and/or are in a period of transition from this dominant self-image, speak to the drug issue in narrower terms. Although they also observe high numbers of consumers currently on medications, they are less willing to entertain thoughts that drug use could (or should) be eliminated.

One suggestion for change was simply that hospitalization experience should entail more than treatment with medications or "medications adjustment" opportunity (Alice Wetherby 1987). Use of major psychiatric drugs was not identified as an issue in itself. Similarly acritical in approach was a suggestion that researchers develop medications that will "cure mental illness," instead of using them as a maintenance treatment for manifest conditions (Martha Wright 1987).

"Cyclical Volunteers'" Perspective

Within this ABC category, persons with recent hospitalization experience recommended that medication use by injection be eliminated in the hospital, but each person offered this suggestion only in the context of changing the way hospital staff relate to patients (Bill Peters 1987; Jeff Bell 1987).

ABC "Guests'" and "Others'" Perspective

There were few change suggestions for medications treatment among people in these ABC identity categories. An understanding of the dynamic that maintains high use of them in the system was noted (i.e., they affect "symptoms" and more easily accomplish alteration of behaviors than psychotherapy), but was not accompanied by suggestions for less widespread use of them (Ben Harris 1987). In fact, one major psychiatric medication (i.e., lithium) was deemed so "effective" for treatment of "manic-depression" it was suggested that the need to participate in psychotherapy, in order to receive prescription for it, be abolished (Ben Harris 1987). Another consumer suggested that current medications use among consumers observed at ABC seemed appropriate, and need for its use was best determined by psychiatrists for involved individuals (Samantha Barker 1987).

One "guest" at ABC hinted at criticism of psychiatric drug use but did not make it explicit. She recommended that many consumers who are currently on "meds" be reevaluated to determine whether they "really need" their prescriptions, and/or whether the medications actually eliminate the symptoms (e.g., "hearing voices") for which they are prescribed (Pamela Martin 1987).

With the possible exception of the above suggestion, recommendations concerning medications issues from all but "consumer advocates" can be generally characterized as predominantly acritical of contemporary trends in major psychiatric drug administration.

Psychotherapy Issues

Nearly all people with whom I interviewed agreed that consumers need to have access to and encouragement from a therapist they trust on an as-needed basis. However, there are discernible differences in approach to issues of psychotherapy among the various ABC identity categories.

"Consumer Advocates'" Perspective

"Consumer advocates" linked the need for psychotherapy to some other facet of need in the consumer experience. Carly Willis (1987 interview) suggested that good therapy, from a person who cares, is "not enough:" the bigger need was for consumers to return to gainful employment and get off the "public dole." Therapy was not solely sufficient to accomplish this in her view. She recommends more attention to vocational rehabilitation programs' effectiveness once a competent psychotherapist is secured.

Suzanne Turner (1988 interview) suggests that psychotherapy _and_ support group participation is more effective than either one alone: support group participation allows a more holistic approach to life's problems. Psychotherapy tends to focus only on that "disturbed self," thus limiting a wider definition of self.

Karen York (1987 interview) also agrees that good psychotherapy is important for consumers, but wishes that the system of mental health care in town would employ more black therapists who might work with black (and other minority) consumers. She believes this would facilitate the therapy, and allow the consumer to feel supported in a larger sense. She contends this will attenuate some of the racist attitudes manifest toward minority consumers in the care system. Among black consumers that she knows, the problem of racism in treatment settings compounds their difficulties in recovery of mental health. She applies knowledge gained through ABC: when consumers model their behaviors after other consumers who are recovering, the results are beneficial. Were black consumers to have access to models that not only had "expert knowledge" on mental health, but also empathy for the special situation of being black in this society, similar beneficial results might ensue.

One suggestion offered (Suzanne Turner 1988) clearly departs from mainstream practices in the field: Upon first admission to a hospital, begin psychotherapy before placing consumer on major psychiatric drugs. This idea emanates from an observation. When consumers are admitted to the hospital, they are painfully aware of issues that impel them to make this choice (or have it made for them through commitment proceedings). Medications sedate and render people less aware of their inner dynamics. Were psychotherapy started instead of medications during the first hospitalization, consumers' return to the community on maintenance levels of psychoactive medications might be avoided.

These change suggestions from "advocates" again evince a broader perspective on psychotherapy issues. Their recommendations, if acted upon, would likely affect significant numbers of consumers.

"Transitional Advocates'" Perspective

Persons involved with ABC who manifest movement away from "mental patient" identity toward embrace of a "consumer advocate" social identity have a somewhat narrower vision of what needs to change in the sphere of psychotherapy issues. Their suggestions clearly derive from their own experiences.

One consumer fantasized about a therapist who would devote undivided attention for days on end to one client, as a way of addressing therapy session time limitations she experienced as frustrating (Alice Wetherby 1987). Another consumer suggested that inpatients and outpatients who are college educated should receive more appropriate messages from their psychiatrists and psychologists, i.e. to resume a "normal life" and engage in "as high functioning projects as they can" (Martha Wright 1987).

The scope of these suggestions is limited. Were such suggestions adopted by practitioners within the system, benefits would be limited to few in the larger consumer population.

"Cyclical Volunteers'" Perspective

One person within this category of ABC involvement expressed a general desire that consumers break their dependency on therapists and/or other providers in the system. However, he did not believe that this precluded the need for a psychotherapist who was compassionate (Jeff Bell 1987). Because Jeff was once at a high level of involvement with ABC and has also been involved with ABC and Steven Ashton for eight years, his system wide perspective on the issue (which dominated the "consumer advocates" commentary above) may better reflect his former position with the organization than his current, and "moderate," level of involvement.

The other suggestion from consumers assuming "cyclical volunteer" roles at ABC typifies the category by attention to pragmatism. Bill Peters (1987 interview) recommends that the therapist consulted during hospitalization be able to accept consumers for outpatient therapy in the community. This would provide continuity in care and opportunity to enhance the emerging trust relationship started in the hospital.

ABC "Guests'" and "Others'" Perspective

People with low involvement in ABC ("guests") and/or those whose interview profiles matched none of the other ABC identity categories (i.e., "others"), also approached psychotherapy issues pragmatically (e.g., in terms of competence and accessibility).

One comment addresses issues of employee qualifications for therapist positions in the care system: More psychologists and fewer social workers should be hired (Ben Harris 1987). This was linked to social workers' alleged inability to proceed with in-depth psychotherapy, due to the training they receive. Psychologists, on the other hand, were viewed as people who could assist during the "end-type therapy," after basic issues (e.g., medications, housing, income source) were resolved.

Another consumer rued the many changes in therapists she had experienced in the system, and suggested that this facet of public mental health consumer experience be avoided (Pamela Martin 1987). She avows that had she been able to work with one therapist over time, much of her later experience in the system (e.g., hospitalizations) could have been avoided. She implies that this may be true for others as well.

Thus, with one exception noted in the "cyclical volunteers" category, the approach to psychotherapy issues among ABC consumers in this sample appear as points on a continuum, from a system-wide perspective to a "mental patients'" perspective to a (largely personal but) pragmatic perspective.

Diagnosis Issues

The belief in the validity of diagnosis constructs is routinely high among consumers in this research sample (with only one exception). This suggests that reification of diagnostic constructs occurs among mental health consumers. I first thought this was a by-product of treatment experiences; but I also found this process at work in social settings. Patterns in interview and field research data suggest that many consumers embrace the idea of specific diagnoses as a 'special community of peers.' Many friendship circles among people with certain diagnoses were predominantly comprised of consumers with the same diagnoses. Even my early field research notes for this project (1983) reflect substantial attention among consumers to their respective diagnoses. It was remarkable how often ABC consumers being introduced to each other would exchange names, then immediately exchange diagnoses!

Given this trend, it was not surprising that many suggestions for changing mental health system operations were broached in terms of special attention to diagnostic categories. The degree of involvement with the consumer-run organization, ABC, does not appear to affect this belief in any significant fashion (suggestions will thus be reviewed as a whole). A sampling of these suggestions include:

-Hospital staff need to handle the stress of their jobs better because this affects the type of diagnosis rendered. Hurried judgments result in "misdiagnosis and damage" (Steven Ashton 1987).

-Rehabilitation programs should be restructured to accommodate the needs of consumers in specified diagnostic categories (Steven Ashton 1987).

-Hospital personnel should teach consumers about the specifics of their diagnosis (e.g., you need this medication, this is what you can expect as a result of your "illness," this is what you shouldn't expect) as a way of easing fear during the first hospitalization (Sarah James 1987).

-A "more extensive system of diagnosis" is needed (Ben Harris 1987).

-Doctors should consult their diagnostic manuals to determine the proper diagnosis. "Proper diagnosis is proper treatment" (Jeff Bell 1987).

All of these recommendations rely on a tacit understanding of diagnosis as a specific indicator for certain treatment needs. Little awareness was expressed that diagnosis constructs, like the overarching construct of "mental illness" which informs them, are subjects of great controversy within and peripheral to the field of mental health. In practice, when I encouraged people during the interviews to comment on specific needs that "matched" certain diagnoses, they unwittingly communicated the basic problem preventing attention to individual diagnoses within the public system. The "specific needs" for certain diagnoses overlapped with many other "specific needs" for consumers in general.

It was this finding that led me to see that although consumers approached and revered diagnostic categories as if they were 'special communities of peers,' the "community" that membership in a diagnostic category offered was transient (diagnoses are often changed) and unmarked by feelings of affinity with other "members" or special socially valued criteria associated with authentic communities. I summarize these findings by referring to diagnostic groups as "psuedo-communities" which consumers embrace when their need for affiliation and relatedness is high (e.g., when social vulnerability or coping difficulty is so extreme that inpatient care is sought).

However, two suggestions for change with respect to diagnosis issues were particularly salient. Martha Wright's suggestion (from her 1987 interview) highlights one routine practice that demeans consumers' potential for recovery and growth, and offers a definition of the situation that can be harmful. She suggests that consumers should not be encouraged to give up vocational aspirations by therapists or other system personnel because of their diagnosis. To effect such a change in the system would require extensive reeducation of currently trained providers and professionals in the field, who are schooled to believe that, for instance, "schizophrenics" should not look beyond the secondary labor market for possible employment. As Martha noted in her interview:

> I had a social worker that said ... with your diagnosis [schizophrenia], the only thing that you're ever gonna become is a secretary and that's it. ... I was intimidated by the system. I felt ... I had a lot of drive, and I really wanted to ... teach at a University. I took it real hard (Martha Wright 1987).[1]

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[1] This kind of insidious communication is not limited to social workers. Other providers, and many researchers, subscribe to the idea that the prognosis for schizophrenia is routinely poor, and its course will likely result in "chronic mental illness" (e.g., see Keith and Matthews in Talbott [ed.] 1984, 7).

Another change offering with extensive ramifications was that "psychiatrists should be required to take recertification boards [i.e., examinations]..." (Jeff Bell 1987). Were this suggestion adopted, it would require that the field of mental health be seen in a more fluid manner, subject to alteration by influx of new knowledge. In current practice, the official journals subscribed to by professionals, as well as intermittent "in-service training" and/or conference participation, are seen as adequate to inform practitioners about changes and/or research developments in the field.

Hospital Issues

Admission Policies: Perspectives On Change

Only people profiled as "transitional advocates," "guests" or "cyclical volunteers" in relation to the ABC organization commented on hospital admission policies. Alice Wetherby (in her 1987 interview) exemplifies the perspective of people who expect that hospitalizations will continue to be part of their experiences (i.e., "transitional advocate"). She comments that voluntary hospitalization achieves better results than hospitalization required by commitment. In this regard, she also noted that sometimes people "are not yet to the point" where they "know they need hospitalization" (Alice Wetherby 1987). The full context of her comments imply that recognition of hospitalization need is an indicator of insight or growth. She did not link these comments to a criticism of commitment procedures nor to belief that hospitalization could ever be avoided. Her suggestion for change is thus an encouragement to consumers to voluntarily admit themselves and avoid commitment.

Another consumer, profiled as a "cyclical volunteer" at ABC, provides criticism of the provider attitude manifested during commitment proceedings. Intake psychiatrists, determining the need for commitment, should not be swayed by previous "mental illness" history. They should treat consumers being evaluated as people (Sally Tisdale 1987). She observes that people with psychiatric histories are not seen as people; their continuing identities as "mental patients" are ascribed on the basis of the past history of treatment.[1] Her suggestion that past history not be taken into account in the present reveals the contemporary, demeaned position of the consumer in the larger society. (Prosecutors of criminals in court settings are not allowed to reveal previous criminal histories lest this prejudice judge or jury; the lack of this provision during commitment hearings demonstrates differential "protection" for consumers.)[2] It is unlikely that this practice will be altered.

A more oblique reference to changing hospital admission policies from an ABC "guest" is provided by a recommendation

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[1] Thomas Szasz (1987) supports this idea as well. "...the presence of this illness is often, and characteristically, inferred from the fact that the supposedly mentally ill person occupies the role of mental patient" (1987, 59).

[2] See Thomas Szasz (1987, 112-120) for a detailed analysis of similarities and differences between treatment of "mental patients," prisoners, and those "accused of the crime of mental illness" (1987, 113).

to introduce more "confederate patients" (i.e., people posing as psychiatric patients) into the mental health care system (Ben Harris 1987). The idea is motivated by a belief that this would enhance "quality control" in hospital settings, especially if staff were alerted to the possibility. While earlier research may support the idea,[a] benefits to consumers in this locale would be limited to first-time hospital admissions. Consumers repeatedly hospitalized would not be affected, unless the threat would cause positive changes in current hospital programs or standard treatments.

Hospital Programs Issues

"Consumer Advocates'" Perspective

Suggestions for changing hospital programs from people very involved with ABC activities addressed issues likely to affect many hospitalized consumers:

-Structured day treatment program should be made consistently available to public and private consumers in the hospital (Connie Hawks 1988).

-Hospital personnel must consider consumers' physical condition before selecting items for "activity therapy" (Sarah James 1987).

-Hospital programs should not be so good that consumers become accustomed to them and/or seek readmission to gain access to them. At the same time, current programs should be altered to avoid isolating the consumer who is hospitalized from the larger community (Connie Hawks 1988).

Concerned with the experiences of their peers as well as their own, these suggestions capture important aspects of the hospital experience. The first one listed (suggesting day treatment for all patients) seeks to equalize the differential treatment provided to private versus public mental health consumers, but also between public mental health consumers (some of whom are excluded from the program).

The second suggestion taps into ways in which consumers are disregarded, and seeks to confront this. When "activity therapists" provide crafts requiring fine motor skills (e.g., stained glass bead projects) to consumers who are taking high doses of major psychiatric drugs, their inability to complete such "a simple task" is frustrating and contributes to an atmosphere of tension. Moreover, if they have been prescribed major psychiatric drugs for a period of time, it is likely that effects of tardive dyskinesia will disrupt attempts to complete such tasks. A recognition of the consumer experience is thus denied. Change in this area could be easily made: it simply requires different selection of activities or crafts by hospital personnel. Very little expense (if any) is involved.

The third suggestion, that programs should not allow consumers to "have a good time" in the hospital, provides commentary on the trend noted among the consumer population using ABC: repeated admission to the hospital. If hospital inpatient programs were "too good," this might provide impetus for rehospitalization. At the same time, programs should be less isolating, providing consumers with opportunity to interact with the larger community in <u>some</u> capacity depending on personal circumstance. This exposure during hospitalization could improve chances that consumers will make a smooth transition from hospital placement to community residence.

ABC "Guests'" Perspective

A suggestion that was not posed in the context of differential treatment for private versus public consumers' hospitalization experiences nonetheless addressed the inequity broached by others in Chapter 6, "Consumers' Treatment Experiences." Programs for hospitalized persons should include physical activities, especially in the mornings (e.g., bowling, swimming) (Pamela Martin 1987). Pamela posed this idea as one which would invigorate consumers and "get their energy up." Whether an effect of depression and/or medications use (or both), it has been observed that many consumers have trouble "getting going" in the mornings. Physical activities made available to public consumers as well as private equalize the benefit of the activity. While the change might require different staffing patterns, and/or possible addition of staff, anticipated benefits might be widely felt (e.g., calmer atmosphere on the public unit, less tension to be "acted out" between staff and consumers, possible decreased staff-turnover from improved working conditions).

<u>Hospital Staff Issues</u>

"Consumer Advocates'" Perspective

Most of the ABC advocates focused commentary about hospital personnel on issues of communication. Their change suggestions seek to alter the customary "definition of the situation" provided to them in the hospital (i.e., as "mental patients," they are incapable; incurable; and dependent). Their suggestions to effect such a change in interpersonal dynamics appear below.

Upon admission to the hospital, consumers should be told more than what they can't do. Hospital personnel should tell consumers what they can do as well (Connie Hawks 1988). That is, they should define consumer's situations (that brought them to the hospital) as a temporary problem. Communicate to inpatients that they can get better (Dana Monroe 1987). Additionally, hospital staff should teach consumers that hospitalization does not solve their personal dilemmas and steps they should follow to avoid the need for it (Sarah James 1987).

The next suggestion was popular with most ABC "consumer advocates," but also was cited by a "guest" of ABC (Pamela Martin): Hospital staff should be primarily comprised of people who have experienced emotional difficulties (Pamela Martin 1987; Sarah James 1987; Karen York 1987; Carly Willis 1987). This may facilitate the suggestion broached by another "consumer advocate:" that staff should assist consumers in making decisions to leave the hospital. Premature discharge due to bed shortage should be avoided (Dana Monroe 1987).

A subtle appeal to alter dominant modes of interaction on hospital psychiatric units is offered by a staff person at ABC. To lessen feelings of isolation associated with hospitalization, hospital volunteers from the community should be assigned to the psychiatric units (Karen York 1987).

This facet of the hospital experience is little mentioned

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by others in the research sample, i.e., a dearth of volunteers on psychiatric units. Many consumers in this sample, and most others at ABC, have experienced moderate to severe rejection from family and non-consumer friends. (This may explain why so many have friendship circles exclusively comprised of consumer peers). Their exposure to the non-consumer population is limited in the community (routinely by virtue of their involvement with the consumer-only organization, ABC), and again in hospital settings. The effect that this small change (at no cost to the system or the hospital) might have on the experience of inpatients could well be significant. Recognition and acknowledgement of the consumer experience only from other peers (or providers communicating specific definitions of the situation) limits access to different kinds of interaction and possible acceptance from others that might broaden their vision of self-as-mental-patient.

(The reason for exclusion of volunteers from psychiatric units may be two-fold: it would be expected, given the depth of stigma and fear surrounding "mental illness" and "mental patients," that few people volunteering to a hospital would ask to be assigned to psychiatric units. It is probable, given this same dynamic, that administrators of the hospital would <u>not</u> assign volunteers there.)

In a similar vein, an ABC "advocate" suggests an alteration of interpersonal dynamics with respect to ward procedures: Hospital staff should talk to people rather than seclude them and/or tie them to beds with restraints or a straight jacket (i.e., the "take-down" procedure). Consumers should not be subjected to these treatments because staff are stressed or upset (Connie Hawks 1988). This perspective is shared by two "cyclical volunteers" at ABC as well (although their emphasis is solely on abolishment of the procedure and less directed to changing interaction patterns).

Another "cyclical volunteer" from ABC again raises pragmatic issues in his concern over discharge conditions: Hospital personnel should ensure that consumers have housing and a source of income prior to discharge. Hospital therapists who worked with the consumer should also arrange for a follow-up call to the person in the community after a specified period of time (10 to 30 days later). Consumers should be allowed to call the hospital where they were incarcerated if problems develop after they leave, and establish a communication-link (Bill Peters 1987).

Thus, an apparent pattern in change suggestions that differentiates "consumer advocates" from those less involved with ABC and/or those not constructing specific ABC self-identity images is again evinced in this section. "Consumer advocates" attend to the larger picture (i.e., changing and/or correcting communications received from staff), and those less involved seek resolution of basic needs (i.e., housing, income source, and establishing connection to providers who can problem-solve for the individual).

Hospital Alternative Issues

Few ideas for alternatives to hospitals were mentioned by people interviewed. There is no apparent pattern in these change offerings that reflect different levels of involvement with ABC and/or self-identity constructs specific to the community. Suggestions are thus reviewed as a whole below.

A non-hospital setting should be arranged for limited use by people who "feel uncomfortable" in the community to avoid rehospitalization or commitment to the hospital (Bill Peters 1987; Steven Ashton 1987). More half-way houses need to be developed as an alternative to hospitalization (Ben Harris 1987; Carly Willis 1987).

Both suggestions rely on the idea of "institutionalizing" people experiencing difficulties, albeit in modified form. "Non-hospital settings" accessible to numers of people, and half-way houses which routinely accommodate no less than 10-12 persons per home, must both operate as small institutions to achieve economies of scale (e.g., purchase food in bulk). Additionally, need for staff to supervise or monitor placements also parrots institutional arrangements. This limited vision of alternatives may be an artifact of the research sample as a unit, i.e., all persons (but one) have had hospitalization experience. Advocacy efforts for/with ABC consumers (whatever intensity with which they are pursued by staff or volunteers) predominantly focus on issues related to such experiences, and do not necessarily elicit attention to nor imaginings about non-institutional alternatives. Smaller institutions (e.g., half-way houses or structured "respite care" provisions) may alter certain procedures in the settings, but they maintain the dynamics between providers and patients found at larger sites (i.e., superordinates "provide" and "define" the situation for subordinates).

Outpatient Programs

There was significant overlap in "change issues" regarding outpatient programs identified by consumers at various levels of involvement with the ABC organization. Offerings will thus be reviewed as a whole.

Programs that allow for individuality, choice of pleasurable activities, and are "realistic" need to be developed (Samantha Barker 1987). More specifically, programs for consumers should be restructured to allow individual needs to be addressed. A variety of programs are needed to avoid forcing consumers into certain programs that may cause them damage (Steven Ashton 1987).

The attitude of the "caregiver" (i.e., provider) determines the effectiveness of the treatment program (e.g., medication prescription, day treatment, occupational therapy). The caregiver must care for consumers, be dedicated to helping them, not look upon them as products nor assume they are superior to them. They must see consumers as human beings (Steven Ashton 1987).

Programs need to be developed that: teach self-responsibility and self-care; how to maneuver passage through the system without damage; and provide referrals to agencies that can actually help (Jeff Bell 1987).

Voluntary and involuntary consumer populations in different programs should be combined. Program personnel should <u>not</u> communicate that attendance is mandatory at some programs because people are "crazy" (Pamela Martin 1987).

Mental health rehabilitation programs should avoid daily routine in activities. They should be restructured to supply participants with incentive or challenge (Bill Peters 1987).

Consumers involved in several "treatment" programs (e.g., group home, day treatment, vocational training) receive some duplication of services. Due to lack of inter-program communication, other areas of consumer need are overlooked. Goal setting procedures followed by respective programs may also be inconsistent, and cause stress to the involved consumer. A staff person should be identified (or hired) who can act as a liaison between programs to monitor these issues (Dana Monroe 1987).

The shared focus of consumers' commentary about outpatient programs is predominantly on the role of providers, and how their input or changed approach to the tasks involved might alter the experience for a number of consumers. Categories which indicate ABC identity constructs and/or differing levels of involvement held in common this focused attention on the provider role. In this selective focus, there is departure from the "advocate" tendency to believe that consumers can change conditions. No suggestions for consumer-impelled changes in outpatient programs were made.

This seems to echo an earlier finding regarding few suggestions for hospital alternatives: the focus of ABC advocacy efforts is on the "as is" experience of consumers in hospitals as well as outpatient programs. This may contribute to a limited vision of bona fide alternatives that consumers might introduce, and instead concentrate attentions on improving a "given" situation.

These responses also intimate other unstated constructions which were discussed in the introduction to this chapter, that tacit recognition of dominant relevance structures for the system of mental health care embody unquestioned assumptions about providers, consumers and programs. Providers' position vis-a-vis consumers is one of greater power and influence, and a determining factor in the outcome of treatment: responses above indicate no questioning of this structured inequality and assume that these relationships will be reproduced again and again, _even if_ consumers' suggestions are incorporated and change the quality of the relationship. Moreover, the problems with existing programs will only be "fixed" by actions of people in positions of power to effect them. These unvoiced assumptions about the perpetuation of a professionalist system of mental health care also posit consumers as unaccountable (for the outcome of treatment) and without power to effect changes in programs.

There was no call for a greater democratization of programs, and little call for consumer involvement in attaining changes suggested. The voices of ABC "consumer advocates" as change agents virtually disappear in this section: this suggests that the anchor for the self-identity construct of "consumer advocate" largely remains tied to the community of Alternatives By Consumers.

Vocational Rehabilitation Program Issues

"Consumer Advocates'" Perspective

Appeals for holistic treatment, and attention to issues that affect attainment of employment (beyond those noted within vocational rehabilitation programs) characterize offerings of people very involved with ABC work.

Programs that focus on vocational rehabilitation should be holistic. They should help consumers deal with a range of experiences (the living situation, the job and tensions it creates, income issues, "and stresses and death") that they could "normally" handle alone but "can't" anymore (Steven Ashton 1987).

Prior to assumption of employment, consumers should be helped to withdraw from major psychiatric drug use since its use interferes with clear thinking (Carly Willis 1987). Employers who are financially able to accommodate the special needs of consumers (e.g., low tolerance of stress) should be encouraged to do so. Work tasks need not be forgiven, but a compromise on work load can be achieved (Suzanne Turner 1988).

Each suggestion in this section describes consumers' in less-than-able ways: they are no longer able to handle routine stress; they cannot think clearly when taking their prescribed medications; and they need special accommodations in order to be employed. While each "advocate" can provide many examples that validate these claims from their work with Alternatives By Consumers, it is from this consumer-as-disadvantaged viewpoint that they offer suggestions so that others can alter situations _for_ consumers. Thus, they unwittingly deny that consumers can alter their own situations. This may be another sign of the process mentioned in the previous section: ABC "consumer advocates" are advocates for and with other consumers who are a part of the ABC community (and frequently for consumers in ABC-affiliated drop-in centers in other geographic areas). Beyond the confines of the ABC community or extended community, the advocacy stance of "consumers can do for themselves" weakens as it intersects with the dominant relevance structures of others (e.g., employers and providers teaching job skills).

"Cyclical Volunteers,' Guests'" and "Others'" perspective

Concerns raised by non-ABC "advocates" again display attention to pragmatic issues. However, many consumers (regardless of their degree of involvement with ABC) mentioned a significant factor, program pay rates, that needs alteration (see below).

Vocational training in the system should lead to a job that is worthwhile and allows people passage to new levels of competence (Jeff Bell 1987). Additionally, incentive needs to be incorporated into current work programs (e.g., "real pay" above minimum wage that provides more than that required to cover

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cover laundry, rent, food, and medications expenses) (Jeff Bell 1987; Pamela Martin 1987; Carly Willis 1987; Bill Peters 1987; Ben Harris 1987; Steven Ashton 1987; Karen York 1987). Job security should be a part of vocational training programs involving work placements (Bill Peters 1987; Jeff Bell 1987).

Moreover, arrangements should be made to provide a job specialist and a housing counselor for people in the community to serve people recently discharged from the hospital. A toll-free number (even if local) should be provided for consumers to use when needing help (Bill Peters 1987).

These offerings attend to issues related directly to vocational rehabilitation and/or facilitate opportunity to participate in it. Compared to "advocates'" suggestions above, their shared focus is more specific and provide no commentary on abilities (or disabilities) of consumers.

Provider-Consumer Relationship Issues

Only one ABC "guest" (Pamela Martin) provided commentary on changing relationships within the mental health care system. All other suggestions, including agreement with Pamela's offering, are provided by ABC "advocates."

Reciprocal relationships should develop between caregivers and consumers. Each should share their perspective (i.e., the consumer is frustrated by their problems, and the caregiver is frustrated, anxious, and sometimes helpless in the face of the consumer's problems) with the other (Steven Ashton 1987). Honest disclosure should be a part of the consumer-provider relationship. A setting should be arranged where the provider admits they feel like they're god, that they have control over the consumer, and that they may be sexist in approach and assume that women are weak. The confrontation over these issues should be conducted in a strong but gentle way (Steven Ashton 1987). Case managers and other mental health personnel should care more about the consumers with whom they work (Pamela Martin 1987; Steven Ashton 1987; Suzanne Turner 1988; Karen York 1987).

Other consumers approached provider-consumer relationship issues from a different vantage point when offering suggestions for change. The "status" or class distinctions between psychiatrists and consumers should be downplayed to avoid making the consumer feel inferior. Psychiatrists should be encouraged to wear something other than business suits or dresses (Connie Hawks 1988). Hospital personnel should avoid emphasizing the "status" distinctions between patients and providers. The segregation of patients to one cafeteria and staff to another, and the designations "patient phones" and "provider phones" should be eliminated (Sarah James 1987).

It is noteworthy that ABC "advocates" seek to apply what has been successful for them in creating the ABC community to provider-consumer relationships. That is, there are appeals for mutual and honest disclosure between parties (the dominant ethos at ABC), and appeals to sensitize both parties to the perspective of the other in a strong but gentle way (a way of "operationalizing" the ABC belief that all are "people first, and people with problems, second" through the ABC vehicle, "gentle justice").

Suggestions that status or class distinctions should be deemphasized can also be seen as appeal for greater sensitivity but it is one way: providers need to do this <u>for</u> consumers, to spare them humiliation. However, awareness of such "status trappings" indicate some level of insight to ways in which professional dominance is maintained in the care system. This consciousness may help consumers alter dependent relations to system providers by unmasking a source of professionals' power. As this process occurs over time, consumers demystify the shroud of authority wielded by professionals and approach them without (subordinate) deference.

<u>Professionals' Education Issues</u>

One ABC "advocate" spoke to concerns about bias in official training received by providers: Formal education about "mental illness" should be altered, as it does not allow room to see the individual versus the diagnostic category into which the person is assigned. In its current form, formal education maintains the stigma of the "mental patient." It also teaches certain prognoses for certain "mental illnesses," and communicates a message of "hopelessness" to consumers. Consumers need providers to communicate hope in their recovery (Connie Hawks 1988).

Like awareness of class or status distinctions, this advocate's awareness of the entrenchment of bias in the formal education system allows another chink in the mystical professional armor to fall away. When she realizes that providers are taught to see clients according to 'diagnostic criteria first and individual characteristics second,' the mystery of making diagnoses is dispelled. Importantly, it also provides a basis from which she can refute insidious messages about self (communicated through the vehicle of provider-defined situations, including rendering diagnoses). Connie sums it up this way: *How can you tell me that I am right there in your book? My name is not borderline, my name is Connie Hawks* (Connie Hawks 1988).

Consumers' Education Issues

Only one ABC "transitional advocate" commented on need for changing system operations according to an achieved attribute: Consumers with college degrees who are in the public mental health system should have different programs developed to suit them. The system should also expend funds to employ college educated consumers in situations where they will be accommodated for their "illness" (e.g., the employer should be told that the consumer will miss periods of work, "a week or more or less," due to their "illness"), and experience no discrimination because of it (Martha Wright 1987).

These comments exemplify the tensions manifest in the "transitional advocate" category. Martha voices appeal for recognition of an attribute valued in society at large (i.e., a college degree) but ignored in the mental health care system. She thus expresses some awareness of the "generic" nature of consumers as a whole. Her commentary is grounded in her own frustrating experience, but she is also aware of the larger picture: there are other college educated consumers who share such problems. These consumers need programs that recognize their abilities.

However, special treatment (i.e., excusal from work without penalty) for college educated consumers who have a job provided by the system is an appeal for recognition on the grounds of an attribute devalued in society at large (i.e., "mental illness"). These consumers need work programs that recognize their disabilities. Thus, as an ABC "transitional advocate," Martha displays an affinity with advocates by seeing part of the larger picture (other college graduates in the system) and also affinity with "mental patients," who require accommodation and acknowledgement without recrimination for their "illness."

Basic Needs Issues

ABC "advocates" (e.g., Sarah James, Suzanne Turner) are aware of basic needs issues for consumers using the organization, some of whom have had personal experience with a deficit in these areas. They are joined in their commentary by a "guest" of ABC (Ben Harris) who sought ABC help during his own lack of housing period. His awareness of the housing problem, and suggestions for addressing it, may in part be an outgrowth of his ABC experience in this area. Additionally, a "cyclical volunteer" for ABC who had trouble locating housing and has sporadically assisted other ABC consumers in their own housing search speaks to the issue as well (Sally Tisdale). She, too, may have an enhanced awareness of the problem through her contact with ABC. Their suggestions are reviewed as a whole below.

Basic needs should be addressed for any consumer in the public mental health system (e.g., food, housing, dental and health care availability, clothing) (Sarah James 1987). Consumers should not be discharged from the hospital or Night Care without other housing arrangements in place (Ben Harris 1987). The mental health system needs to ensure that consumers have "secure and private housing" in addition to a source of income (Sally Tisdale 1987). Housing situations for consumers should be arranged which recognize the financial risk the rental agent assumes (e.g., through damage of property by consumers in emotional turmoil). Subsidies should be available to rental agents willing to assume this risk (Suzanne Turner 1988).

It is noteworthy that Suzanne Turner, an "advocate," connects the consumer housing problems to knowledge of the larger dynamic, i.e., financial risk to the rental agents. She sees a relationship between housing discrimination and a financial reality. From her work at ABC, she knows that consumers sometimes damage their housing sites, more commonly referred to as "trashing their apartment." Whatever the motivation for the behavior, the consequence is financial cost to the person renting out the facility. There is frequently consequence to the consumer as well: eviction, and/or hospitalization, and/or temporary homelessness which may well continue because their last rental agent will not give them a recommendation for housing to other rental agents.

Were the system to recognize both this propensity on the part of consumers and the significant financial strain this causes land owners, a broader base for subsidizing land owners assuming the rental risk would be needed. The solution to the problem is redress by the system, rather than attention to the needs of persons who have reached a point where they can no longer control the impulse to "trash" their living environment. This latter conceptualization of the problem may also be an effect of Suzanne's work at ABC: most situations where people "act out" rather than verbally express the frustration or ire they may be experiencing (other than in hospital settings) routinely occur when they are alone. It would thus be difficult to use a "preventive" approach to such a problem, without requiring consumers to live in group settings.

Residential Placement Issues

Experience with supervised housing situation provides the basis on which change suggestions in this area are made. No apparent pattern in suggestions and ABC level of involvement of ABC related self-identity constructs are evident, so suggestions will be reviewed in this section without division into ABC categories.

More Adult Foster Care (AFC) home placements should be used for consumers. This kind of residential placement allows more authentic expression of emotion without recrimination than allowed in the hospital (Connie Hawks 1988).

The "step program" (e.g., a token system where consumers earn points or privileges for compliance with specific rules) in group homes should not be presented in its current fashion. Consumers are told that they do not need to leave the home when they earn the highest "step level" (Connie Hawks 1988). In practice, once this step level is obtained, consumers are asked to leave when need for his/her bed arises (Connie Hawks 1988; Alice Wetherby 1987).

When Alice tried to challenge this practice, by not applying for her "step" to be raised when she had met criteria for doing so, the staff of the home applied for her. When she subsequently asked that the "step" be lowered because she was being "moved up too fast," the staff acquiesced, but only for a brief time (Alice Wetherby interview 1987).

In this section, Connie, as representative of the ABC "advocate" perspective, speaks to an issue affecting many consumers (i.e., AFC home placement). She also can agree with Alice's "transitional advocate" perspective on the group home issue, having shared a similar frustration in her past. Her initial approach, however, distinguishes her "consumer advocate" position at ABC: she speaks to a concern that group home staff offer "false promise" in the conditions for placement. In this approach, her awareness of the impact of provider communication on consumers is primary. She is joined in her comments by the "transitional advocate" only when the issue is focused on specifics of "patienthood:" that is, the conditions which impede continuing residence (of "mental patients" needing supervision) in the home. In essence, the "consumer advocate" reacts to "false promises" (a wide perspective) and the "transitional advocate" to disruption of treatment needs (a "patient" perspective).

System Expansion Issues

"Consumer Advocates'" Perspective

Consumers who are aware of the fragility of the mental health system budget rarely make explicit their desire that more funding be devoted to consumer care provisions. ABC consumers may be particularly alert to budgetary issues, as the operations of ABC have been affected as much by lack of funds as it has by threatened loss of funds. However, their change suggestions often rely on this unstated premise.

Dependence on system expansion to meet needs and lack of ideas for alternatives to it are common throughout the sample, regardless of consumers' level of connection to ABC. ABC's own dependence on the system for funding may partially explain this effect: their expansion is contingent on the expansion of the mental health care bureaucracy. Nonetheless, ABC advocates tend to suggest expansion of system from a broader perspective: their ideas will affect many consumers if enacted. Three important ideas represent their perspective below.

Hospitals should provide more inpatient bed space and more developed programs (Carly Willis 1987). It was not made explicit during the interview, but this request for increased inpatient accommodations may be related to consumers' experience with premature discharge from, and/or refused admission to, the hospital due to bed shortage. This was found to be a source of great stress, often exacerbating coping difficulties for which consumers sought hospitalization.

However, Carly's commentary on this need was quickly qualified during the interview: To avoid becoming "addicted" to inpatient treatment, provision of additional programs in the community are needed (Carly Willis 1987). Moreover, a greater variety of programs is needed in the community. This would obviate the current practice of consumers repeating the same program 7-8 times (Karen York 1987).

Carly was the only person in this research sample who used the terminology "addicting" with respect to hospitalization patterns (and/or to patterns of behavior with respect to caretakers within and outside of the hospital), but a case can be made that this applies. Addiction is characterized by insatiable desire that does not abate unless fulfilled. Patterns noted in several sections of the "Consumers' Treatment Experiences" chapter (number 6) certainly qualify, especially with respect to behaviors reported following refused hospital admission. Other aspects of inpatient behavior might also be regarded as an addiction, e.g., self-harming behaviors which guaranteed staff response. Another attribute of addiction is unrelenting attention devoted to the topic involved: this could be applied to "transitional advocates," who diverted most of their interview responses to the topic of hospitalization experiences, and some who constantly referred to medications issues (or both). It is also revealed in what they fantasized about: the perfect hospital, the perfect therapist, and medications that will cure.

For many consumers, hospitalization experiences, like diagnostic categories, were constructed during the interviews as a type of 'special community,' although the features offered for "members" of the hospital 'community' were different than identified for diagnostic categories (reviewed earlier). A hospital provides protection, guarantees of staff attention, access to peers, and a haven from coping difficulties or extreme social vulnerability felt outside its walls. In the absence of meaningful community-based vocational and/or rehabilitation programs, hospitalization is a continuing option which provides some semblance of connection to others. "Addiction" to the hospital setting is thus facilitated by community program offerings that are inadequate and/or eschewed by consumers who feel they do not address their real needs. Karen, as the ABC drop-in Director, may have a special avenue of insight into this facet of consumer experience: when consumers do not attend their mandated (or voluntary) day programs, they frequently come to the ABC drop-in instead and voice their displeasure at the program offerings.

Some consumers can recognize and acknowledge the addicting nature of system treatment, especially with respect to inpatient care. Although few use such direct terminology, the sentiment is expressed nonetheless. An expressed appeal for system provision of better and varied programs in the community is related to this unspoken understanding.

ABC "Guest" Perspective

Because ABC "guests" are at a low level of involvement with the ABC organization, suggestions for expansion of the mental health system are not always filtered through the consumer "lens" "advocates" frequently use. Moreover, some "guests" have greater involvement in the larger community (and less in the mental health system) than other consumers using ABC, which afford them a different slant on what community-based, non-mental health related services might be useful to consumers. The following suggestion demonstrates this dynamic.

The mental health system should encourage participation in community colleges, and avoid consumers' dependence on institution-based programs that are "out of touch with what the economy is really doing" (Ben Harris 1987).

I believe that this idea is sound, and one that could easily be accommodated. Its potential benefit is significant: not only would consumers break the cycle of interactions only with other peers (which limits exposure to different ways of being in the world as much as it protects consumers from others' ridicule and stigmatization), it might also broaden horizons of what is possible for them to achieve. It has been revealed that current programs tend to focus on attainment of secondary labor market jobs or job skills (e.g., janitorial, grounds maintenance, short-order cooking, washing dishes, etc.). Community colleges, however, have broader programmatic offerings which keep pace with needs in the economy as a strategy necessary to draw students. Thus, were consumers to tap into use of community colleges, they would have access to classes that might teach them computer skills, electronics, mechanics, etc. Some of these areas of study might well lead to vocations in something other than the secondary labor market.

Many people communicated to me during the interviews that they wished they could return to school, complete their degree, specialize in a certain field of study, etc. They offered a wide range of reasons why they couldn't do so: fear of other students, fear of failing _or_ succeeding, lack of time, inability to concentrate because of their psychiatric medications use, and lack of funds. Although people receiving Social Security Administration disability benefits (i.e., SSI or SSD) are eligible for tuition subsidies, they rarely make use of this opportunity.

Were the system to expand its connection to community colleges, and/or launch a campaign to encourage more consumers to apply for tuition relief under disability benefits' provisions, the potential benefit for consumers would be considerable.

Changing System Operations Issues

There is some over-lap of ideas between the various categories of ABC participants reviewed here. People who are ABC "consumer advocates" again manifest attention to the broader picture vis-a-vis system operations. Their suggestions, if taken, would impact many consumers' experience in the care system. "Transitional advocates" from ABC focus on issues central to the continuing "patient" experience. The lens used to offer change suggestions is narrower than that evinced in advocates' suggestions.

"Cyclical volunteers" express an awareness of broad issues more characteristic of advocates. But their suggestions differ from advocates in a more pragmatic connection to change: consumers would benefit from their change suggestions if adopted, but only if they were affected by the areas in which operations would change and/or if they were hospitalized patients.

The ABC "guest" representative in this section argues for allowing consumer voice to affect system operations; but also presents an idea which would deprive many consumers and prospective consumers of customary civil rights. His simultaneous identity with and rejection of the consumer experience typifies persons at low levels of involvement with the Alternatives By Consumers organization.

"Consumer Advocates'" Perspective

Adovcates contend that consumers' have something to offer the mental health system and the larger society, accorded by virtue of their experiences. To wit, providers and other societal members should be encouraged to respect consumers as people with "expert" knowledge about troublesome emotional conditions. To facilitate this change, consumer-run organizations, like ABC, should be incorporated and required in all Community Mental Health systems (Suzanne Turner 1988).

More specifically, consumers' evaluations of system operations should be solicited. That is, because consumers are authorities on dominant modes of treatment (e.g., hospitalization, major psychiatric drug use), their input should be considered by providers and professionals in the mental health system (Sarah James 1987).

Other change of operations suggestions focused on the disability benefit system. Consumers on disability benefits should be afforded more opportunity to supplement their income by working before their benefits end or are reduced (Suzanne Turner 1988).

Suzanne has captured the essence of the benefit trap that many consumers in this sample have talked about: some would risk a return to employment if the risk did not potentially jeopardize the income that guarantees them subsistence. Others forgo attempts to return to the work force because their income is guaranteed whether they do or not.

Most consumers in the public mental health system (representative of a "typical" ABC consumer) are eligible for SSI (social security supplemental income), which is set on a scale. If income over $14/week ($60/month) is received, the check is reduced by the same amount. Consumers who have previously worked in non-sheltered employment are eligible for SSD, which provides a 9 month "trial period," during which time their SSD (social security disability income) check continues to come monthly, regardless of the level of income they are currently making.

Thus, the system bias in benefit assignment is revealed: consumers who once worked receive higher levels of income and an additional protection of that income; consumers who have not entered the work force receive lower monthly checks and only a $60 "grace amount" before their benefits begin to erode for working. This means that the poorest consumers are the least protected. When they risk losing benefits to return to work, they not only risk their guaranteed income, but if they return and later lose their job, the period of reapplication for SSI may well render them homeless during the hiatus in benefit receipt.

Changing system operations in this respect would involve enhanced inter-departmental coordination between Departments of Mental Health (DMH) and Social Services (DSS). (DSS administrates social security benefits for the mental health system.)

"Transitional Advocates'" Perspective

Change suggestions here focus on assisting only certain segments on the mental health consumer population. The first appeals to system providers to make good on their promises: If Community Mental Health agencies tell consumers they will start a given program (e.g., a program for "high functioning adults"), they should do so (Martha Wright 1987).

The isolation experienced by college educated and/or "high functioning" adults (i.e., those with self-care skills, work histories, trade skills, etc.) in a public mental health system can be profound (Martha Wright and Ben Harris interviews 1987). When consumers with previous access to private mental health care become public mental health system "clients," the experience can be even more devastating because the difference in opportunity is known.[1]

The second suggestion would affect consumers receiving disability benefits. The application process for disability benefits should be reorganized to make it less confusing; make it possible to deal with one, rather than several, people during processing; and shorten the delay in beginning dispersal of benefits to consumers (Martha Wright 1987).

Individual disappointment and dismay may have motivated these latter suggestions, but exposure to the common disadvantaged community-living standard among ABC consumers with whom Martha interacts as a volunteer reminds her of its salience in continual fashion. Simplifying the application process would allow more eligible consumers to receive disability income and allow continuity in the standard of living (even if only at subsistence levels).

"Cyclical Volunteers'" Perspective

In this section, we find echo of a need cited by advocates earlier: consumers must have a say in the workings of the system. Through this opportunity, possible negative

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[1] This is in contrast to public mental health consumers without private care experiences. They may hear others refer to different quality of mental health services, therapy, hospitals, etc., available in the private sector, but they are distanced from it. The difference is only apparent, not known.

communications about self can be negotiated (at least) or altered (at best).

Thus, consumers should have opportunity to provide input on programs they use, and not assumed to be unable to think because they have "emotional problems" (Bill Peters 1987). Communications from providers should not depend on their need to maintain employment and professional dominance. Therefore, system providers need to operate in less "self-centered" ways, and not encourage continuing "illness" or dependency just to keep their jobs (Jeff Bell 1987).

In a similar vein, to ensure objectivity of the civil rights advisor for consumers (i.e., workers in the Office of Recipient Rights), he or she should not be paid by the hospital or the state (Jeff Bell 1987). Changed operations in the Office of Recipient Rights (i.e., the federally funded agency which acts as guardian to "mental patients'" civil rights) would likely affect all consumers in an indirect fashion, but would benefit hospitalized patients the most.

Some change suggestions for the mental health system involve people outside its immediate realm. Police officers and "people with power and authority" should be educated about consumer issues and experiences (Jeff Bell 1987). The tacit assumption in this idea is that additional knowledge will alter behaviors and interaction patterns between consumers and people of authority. Accountability for the quality of interaction is judged as belonging to 'people in power and authority.' Consumers, in contrast, are posed as unaccountable for interaction patterns. Authority figures are proactive; consumers are reactive. The notion of consumer agency, i.e., people who can initiate change, is absent in this suggestion.

Although there is some attention to the monopoly that providers hold in ability to define the situation as it applies to consumers, these change suggestions rely on others to alter behaviors (e.g., providers and police) which have an impact on consumers, and/or specific segments of consumers (e.g., hospitalized patients).

ABC "Guests'" and "Others'" Perspective

One suggestion for change from an ABC "guest" applies to all consumers. Consumers should be able to evaluate staff with whom they interact in programs or hospitals, and system providers should listen to and consider their input (Ben Harris 1987). Having "voice" in system operations allows a different sort of quality control, i.e., from consumers of services to providers and/or administrators of the services. This contrasts to the customary workings, where quality of service is defined, planned and provided according to management criteria.

The language used in the following idea may reveal more about perceptions of the system than the comment itself. (I believe its use was unintended.) The <u>"mental illness system"</u> should be run more like a "business." Administrators should avoid promoting people who are incompetent and may adversely affect consumers in their care (Ben Harris 1987). Substitution of "mental illness system" for "mental health system" provides commentary on the "as is" nature of the system. The appeal is again for more quality control in the workings of the system, albeit from a more distanced vantage point.

A program first adopted in New York City provided a model for another change in system operations. A program should be developed for this locale that designates a search for "street people" be undertaken in certain areas of the city. They would be taken to a site where they would be diagnosed and inculcated into the system, to "help them." All persons encountered in the search would be mandated to participate in this program (Ben Harris 1987).

The ABC "guest" representative for this section presents an interesting paradox in the ideas for alteration of system operations. In the first instance, consumers have viable commentary on staff practices within the system, but in the latter instance, any commentary consumers (or prospective consumers) might have about being forced into the system is deemed invalid. Moreover, consumers' input was <u>not</u> linked to prevention of erroneous promotion of system providers, although its consequence was deemed harmful to consumers as a whole.

I believe this paradoxical stance is related to a low level of participation in the Alternatives By Consumers community. There is expressed alliance to some consumer issues (e.g., treatment rights) and expressed valuing of consumers' informed opinions, but a certain rigidity about priorities that "ought" to apply to consumers (i.e., civil rights are of secondary importance to treatment rights). This latter application seems tied to social stock of knowledge definitions of "mental illness" conditions and "appropriate" treatment of them.[1] In contrast, valuing consumers' informed opinions appears to be an outgrowth of personal treatment experiences and/or shared experiences in treatment settings where consumers' knowledge was deemed legitimate, if not insightful. Such commentary exemplifies the variable affinity for consumers' perspectives shown by people who constructed their self-identity at ABC during interviews as "guest" only. It is at the intersection between private troubles (i.e., treatment experience in poor quality programs) and public issues (i.e., problem of homeless people judged as "mentally ill") that the tension in paradoxical positions is most evident.

Change Issues at ABC

Change suggestions for ABC can be largely characterized by appeals for organizational growth: more money is needed for staff, daily operations' costs, and/or to refurbish the building where the ABC center is located. Organizational growth is also broached in terms of need for additional volunteers, with capacity to advocate in community situations and/or through public forums. Suggestions that would affect the structure of operations or the structural position of the organization

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[1] I note this connection because it is important to this discussion. I do not intend to discount the legitimate controversy that occurs among many advocates for mental health consumers about the relative importance of treatment rights versus civil rights. For a comprehensive discussion of this controversy, see e.g., Lecklitner and Greenberg (1983, 422-430).

within the matrix of service providers in the city are offered by people the least familiar with the philosophy that supports ABC: "gentle justice" advocacy, where all are treated as "people first, and people with problems second." Suggestions are reviewed as a whole due to substantial areas of overlap, apparently unrelated to level of involvement with ABC (with the exception of those noted above).

ABC is something that is desperately needed on a much larger scale (Alice Wetherby 1987). ABC needs more funds (Alice Wetherby 1987; Steven Ashton 1987; Jeff Bell 1987; Sarah James 1987; Dana Monroe 1987; Karen York 1987; Bill Peters 1987; Martha Wright 1987; Carly Willis 1987; Samantha Barker 1987; Suzanne Turner 1988; Connie Hawks 1988). With more money, ABC could fix up this old house and make it nicer (Karen York 1987; Samantha Barker 1987). These suggestions rely on the notion that more money will allow the organization to grow and/or improve accommodations for people using the ABC center.

Suggestions in this paragraph connect increased opportunity for advocacy efforts to greater funding levels: ABC needs to do more advocacy work (Bill Peters 1987; Jeff Bell 1987; Sarah James 1987). ABC should do as much advocacy work as it did in the early 1980s, but there aren't enough people to do it (Steven Ashton 1987). ABC needs another consumer employee in the Help Project, whose only job would be to advocate [i.e., talk to and/or problem-solve] with people coming in to the office. A different employee should handle the record-keeping part of the job. It's too much for one person to do both advocacy and paperwork (Connie Hawks 1988).

Volunteer issues at ABC received a considerable amount of attention: ABC needs to supervise and/or screen its volunteers better (Pamela Martin 1987; Sarah James 1987; Connie Hawks 1988; Ben Harris 1987). ABC needs to figure out a way to recruit volunteers who are more capable, and who can handle a wide variety of tasks (Alice Wetherby 1987; Carly Willis 1987; Connie Hawks 1988). ABC staff should train volunteers and encourage consumers with college degrees to participate in the organization (Sarah James 1987).

There is recognition of the continuing problem with volunteers at ABC: very few are capable of handling the entire range of situations encountered as a volunteer. Those that do volunteer receive inadequate guidance or do not volunteer on a reliable basis. The notion that college educated consumers would be a boon to ABC is not widely shared. Knowledge gained through experience is accorded greater social value by members of the organization.

In light of these recognized problems, suggestions for altering procedures used with ABC volunteers were also offered. Volunteers for ABC should have a support group and planning meeting every two weeks (Connie Hawks 1988). Another consumer suggested a similar idea, but recommended the volunteer meeting be unstructured. When ABC volunteers are at the center, have a spontaneous meeting that includes people visiting that day, and brain-storm for suggestions about things they'd like to see at ABC. Be sure the suggestions are written down and collect them for a few weeks. Then act on good suggestions that are within reason (Sally Tisdale 1987).

"Regular" and/or "cyclical volunteers" of ABC note that a lack of structured opportunity for volunteers to communicate with each other causes difficulty. The difficulty is connected to being thrust into a decision-making role when trying to problem-solve with another consumer. Without a reference group of other volunteers with whom to consult, some people become uncomfortable with "winging it" and suggesting resolution to the dilemma presented based on their knowledge or opinion alone. These concerns about the variable nature of organizational processess overlap with a sentiment that too few activities are generated by people using the center. Structured opportunities for exchange of ideas that goes beyond volunteer to volunteer (or volunteer to staff) would facilitate a shared opportunity to generate ideas for an agenda of activities as a group.

The following suggestions depart from those above, which do not refute the purpose of the organization, nor the benefit afforded to consumers through unstructured opportunities.

> -ABC could have one structured event everyday that would involve everybody using the drop-in; like a topic they could each talk about, or a project they could all help with (Martha Wright 1987).
>
> -It isn't good that people can come here day after day and just sit around. ABC consumers ought to be diverted into different programs from here (Ben Harris 1987).

Unfamiliarity with the idea behind unstructured activities and provisions of a "safe haven" accorded by a consumers-only drop-in center are revealed in the suggestions above. At the time of the interview, Martha had worked as a "regular volunteer" at ABC for about one month. Her previous involvement level had been low; this suggests that unstructured operations at the ABC drop-in program may first appear to guests as an oversight, rather than a deliberate organizational approach.

Ben Harris, as an ABC "guest," provides critical commentary on the function of the ABC drop-in as a stopping point rather than a stepping stone to consumers' further growth. While there is disdain in his comments for those who would "sit around all day," there is also hope. In his vision, were the function of the drop-in altered, growth and change for consumers could occur.

Another activity which could best be handled by ABC was recommended by Sarah. A telephone number should be provided to the larger community to service calls about "mental illness." All questions posed should be respected and not judged to be stupid, even if basic (Sarah James 1987). Were ABC the organization named to provide the answers to community questions, several concerns raised by consumers' could be addressed simultaneously. People helping with the phone lines would have interaction with someone other than mental health peers; consumers would have potential opportunity to alter widely held myths about "mental illness" and "mental patients;" the organization could receive greater visibility and credibility in the community; and most importantly, it gives the opportunity for consumers to enhance feelings of self-worth. When they are able to help peers, they feel better about themselves; there is no reason to expect that this wouldn't occur as they provide information to others in the larger community. Moreover, this outcome might extend beyond benefits of one-to-one "advocacy," which sometimes occurs in isolation from other ABC consumers and staff, and lead to a larger sense of belonging.

"Phone line" services would require a coordination among those answering the lines and some structured training would be necessary to ensure a base line consistency in responses offered to the public. In latter regard, such requirements might prevent the establishment of this service at the organization even if funding were given for it. Their one-time experience with formal training of volunteers proved very stressful for participants and was never attempted again (this training was reviewed earlier, in Chapter 5). It may thus be unlikely that ABC would risk such a structured project.

We turn next to the problem of stigma and suggestions for its redress by consumers of ABC, whose experience with this process has been extensive.

Stigma Issues and Change

The problem of stigma was addressed by every person with whom I interviewed, either in direct fashion, with illustrations of how they have experienced stigma themselves, or indirectly by citing this as a continuing problem for people in the mental health system. The trends that appeared in the data concerning the issue of stigma (e.g., historical approach, need for interpersonal contact with a person labeled "mentally ill," comparison to other grass roots movements) were unrelated to the degree of connection to ABC, so ABC identity and involvement categories (e.g., advocates, transitional advocates, etc.) are not reviewed separately.

The following passage is an articulate rendition of the historical perspective on this issue that many consumers used to exemplify the enduring nature of the problem. It departs from others' historical perspective by implicitly relating current problems with the issue to the advent of deinstitutionalization.

> I think ... we should open everybody's eyes. (laugh) I do ... it's ... so far away, 20,000 years probably, but when people started having emotional problems, ... they were scared of it. ... 'This person's crazy, we can't hang around them.' ... I don't feel it's so much to do with us ... [or] with ABC ... [or] with the hospitals. ... If somebody had a problem at home, and the ... relatives could not deal with them cause they didn't know where they were coming from, it was totally ironic for them ... what are we going to do? So they found out about mental hospitals ... all the people that were ... quote crazy, [were] kept in the hospitals. Locked up. And ... kept for so long. And now the people are out. ... Now that we are out and are bettering ourselves, they don't believe us: ... 'she was in the crazy house. She must be crazy. I wouldn't hire her. I wouldn't rent to her. I've heard of her before' ... (Connie Hawks 1988).

Connie has captured the essence of the historical process of stigma in the preceding passage. People in this country have been conditioned, through observations of the "treatment" of people labeled "mentally ill," to believe that persons manifesting severe emotional problems should be removed from families or residential placements in the community. The effect of the conditioning has less to do with present day consumers than it does with the unchallenged assumption that the people were removed because of some deficiency or danger presented to family members of community citizens. Now that they are in the community again, via mandated deinstitutionalization, no additional education or sensitization has occurred that would facilitate a less prejudiced view of "mental patients." The pejorative view of the consumer of mental health care continues, unabated, to the present.

Steven Ashton speaks to this latter issue, and explores reasons why this attitude has maintained. He links his observations to a need for change. As members of this society, all people are prone to certain biases and prejudices. Unless educated or sensitized to the prejudices they hold, discrimination will continue (Steven Ashton 1987). Connie brings the issue to the interpersonal level, supporting Steven's comments but also linking the idea to the unstated notion that the "personal _is_ political."[1] Judging others according to personal standards of ethics maintains discrimination within the mental health care system and the larger society (Connie Hawks 1988).

Others suggest that to eradicate stigma against people being treated for emotional problems, more exposure is essential: Consumers need to become more visible in the community to assuage the stigma against them (Martha Wright 1987). Members of the larger community need to be exposed to a

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[1] This phrase represents a cornerstone tenet of feminist theory. (See, e.g., Keller 1983, 16.) As applied here, it reveals that the nature of interpersonal relations carry political import.

"mentally ill person" to eliminate the current stigma levied against consumers as a group (Martha Wright 1987; Jeff Bell 1987; Karen York 1987; Carly Willis 1987). For instance, bus drivers need to be sensitized to consumer behaviors and their meaning. They can learn that talking to people who are talking to themselves allows them to engage in "normal" conversation for a while (Dana Monroe 1987).

To illustrate the need for visibility and contact as the vehicle to effect change in the nature of stigma accorded to mental health consumers, analogies to other rights' movements were frequently made: civil rights was mentioned frequently, as were the gay/lesbian rights' movements and the womens' movement. Martha presents a cogent and interesting comparison between the state of the womens' movement some 80 years ago and the current prejudicial situation for consumers:

> The [prejudice against] mentally ill is ... still way behind. I think we're back to where the women were at the turn of the century, where they were fighting for their rights to vote and the majority of women were so silent about it. ... We're at that silent aspect, where ... there's a prejudice going on, but nobody talks about it. ... At least we can look to the gay/lesbian rights activism now ... and see it as a model of what to do, how to behave. Womens' rights [movement] also [gives us a model]... (Martha Wright 1987).

The idea that other grass roots movements can provide a model to consumers was an oft-repeated theme in these comparisons. Other movements were also used (as Martha did above) as a kind of yard stick to measure both the possibilities of change and the distance from change for present-day consumers. Notably absent in all comparisons was the notion that stigma and oppression were linked and that consumers shared a situation of oppression with other groups. Unarticulated insight into this shared condition may have impelled some comments in this area, but manifest expressions that concretely linked situations were omitted.

Other offerings for combating stigma against consumers were broached in terms of "mainstreaming," in direct and indirect ways. "The mentally ill [should be] merged into society like anyone else." This can be facilitated by allowing hospitalized consumers to enroll and participate in college courses as part of their rehabilitation plan (Martha Wright 1987). Within the hospital, inpatients should be encouraged to assume traditional sex roles and engage in [heterosexual] dating (Ben Harris 1987) to lessen their "difference" from others once they return to the community.

Another "mainstreaming" appeal for change was couched in altogether different terms: Consumers should be encouraged to lie on employment applications, and omit any history of psychiatric treatment (Ben Harris 1987). In this view, stigma can be addressed by denying the ascribed attribute on which the process is focused.

Thus, there is wide-spread awareness that stigma continues and affects people labeled in psychiatric terms. There is near-unanimity in suggested approach to the problem: more visibility for consumers in the community and enhanced opportunities for non-mental health consumers to relate in meaningful ways to consumers in the care system.

Conclusions: Trends in Suggestions for Change

"Consumer advocates" at ABC tend to see the "larger picture" of the mental health consumer experience. There is an expressed sense of "the others" who share (or who will later share) certain circumstances within the mental health system. Their problem-solving approach to deficits in the system of care are painted with a broad swath. They believe that the mental health system can change, but this belief is tempered by realism. Change takes time and the issue is entwined with other societal problems: attitudes toward minorities and consumers, conditions of the economy, and the dominance of professionalist ethos in the care system. Also expressed was an awareness of the power differential between consumers and system functionaries, with suggestions for its attenuation and/or note of the ways in which it was maintained through institutions of society (e.g., formal education systems). The notion of change through different kinds of interactions with providers is primary for this cohort. They suggest changing negative communications by establishing reciprocal, equalizing relationships with providers and professionals.

"Transitional advocates" at ABC expressed little belief that the mental health care system can change. Their ideas for change or needs resolution in the mental health system tended to be more personalized and less pragmatic (e.g., a medication that will cure; a fantasy therapist). When their work at ABC exposed them to situations that impinged negatively on their peers in the system, they then raised issues that were broader in scope (e.g., discrimination in housing). Overall, their self-interest in treatment for hospital or community-based "patients" outweighed their attention to "generic" consumer interest in change.

People constructing their identities at ABC as "cyclical volunteers," "guests" and/or "others," corresponding to moderate and/or low levels of involvement at the organization, also spoke to consumers' system-related problems. Their approach was more pragmatic than either "advocates" or "transitional advocates." They tend to focus on issues that would assuage the stigma of "mental patient," e.g., attainment of employment, independent housing, higher education, adequate and secure income. Despite occasional exception, as a group their responses were in contrast to ABC "consumer advocates" who "took for granted" the experience of stigma and instead looked toward how to assuage it for other consumers. This finding suggests that individuals less involved with ABC use a pragmatic but personal baseline from which their change suggestions emanate; those with more involvement in the organization do not.

"Guests" and "others" in the sample generally rejected the idea of consumer-impelled system change (there were a few exceptions, however). Their view of change was generally fatalistic. The issues that impact the lives of mental health consumers could not or would not be changed: the notion of "that's the way it is" was applied to conditions in society (e.g., the job market) and the conditions of individual consumers (e.g., some need medications for life). They shared an underlying assumption that consumers have no control over events in the larger society or within the mental health system. Their suggestions for change largely relied on innovations exhibited by others to which consumers might connect and benefit (e.g., enhanced use of community colleges for consumers).

These categorical reflections suggest that becoming involved with the consumer-run organization, ABC, affects the type of change offering consumers identify as needed and the vantage point assumed when recommending need for change (e.g., from a patients-only versus consumer population viewpoint). It is equally possible that people become involved with ABC because they hold such views.[1] However, my years of involvement with the organization and my personal knowledge of many other consumers' experiences with ABC (observed during two years of ABC employment), complement the informed speculations I offer here.

While differences between recommendations offered by people in the various ABC categories of involvement could not always be clearly demarcated, the patterns that did emerge suggest that people at ABC come to view relationships within the care system and aspects of system offerings in distinctly different ways over time.

The implications of these change suggestions for policy,

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[1] These cross-sectional data do not permit causal inference to be made about the consumer population as a whole or about the larger population of ABC consumers participating in the organization.

practice and program development or operations will be assessed in the final chapter of this manuscript. One comment about the content of these suggestions appropriately precedes an in-depth discussion of policy ramifications, however. In general, suggestions for change offered above cannot be characterized as innovative. Rather, they reveal the actual practices of system personnel and the actual operations of the programs. Reflection on negative outcomes for those who partake in system offerings render certain issues and recommendations for change salient. Recipients of mental health care services collectively ask that the system operations and relationships within it be improved; in large part their request is an appeal for the system to operate as it was intended to operate. In their exposure to a community of consumers, through their contact with ABC, they learn more about others' lack of benefit from actual operations from the system and learn to recognize areas where change would benefit those involved. For most people in this sample, it appears that as their level of involvement in ABC activities increase, they gradually assume a more critical stance vis-a-vis system operations as their base of experiential insight grows.

It is this broadened experiential base of knowledge that allows "advocates" to develop system critiques that apply to significant numbers of consumers, while those with less knowledge of other consumers' experiences develop more particular critiques in certain areas of treatment or programs. At the same time, close attention to consumer population issues sometimes precludes vision of other non-system possibilities which "guests" can sometimes recognize while "advocates" will not (e.g., benefits of higher education, enrollment at community colleges). In sum, their suggestions teach us more about the system as is and less about what it might become. These unstated possibilities for system alteration will be explored in Chapter 10, where I offer policy recommendations for system change that expand on the issues raised by ABC participants in this chapter.

The next chapter begins Part IV, "Conclusions of Study." Before turning to summary policy suggestions in the last chapter, I first present details of the grounded theory of mental health consumerism that emerged through inductive analyses of the research data reviewed in earlier chapters in the following Chapter 9. The key feature of this grounded theory, the notion of social vulnerability, is used as a springboard for developing a tentative theory with applicability beyond the population of mental health consumers, i.e., the theory of social vulnerability states.

CHAPTER END NOTES

(a)David Rosenhan conducted experiments with confederate patients in hospitals (for details, see Rosenhan, David L. On being sane in insane places. *Science* 179 (January 19, 1973): 250-258).

In the wake of the experiments, one hospital director was told that plans were being made to introduce other confederates to the hospital in the ensuing three months. "Of the 193 patients admitted to that hospital during that 3-month period, 43 were culled out by the hospital staff as pseudo-patients. Even the psychiatrists rated 23 of them as pseudo-patients. However, as Dr. Rosenhan explained, 'none were pseudo-patients. Our pseudo-patients got the flu and never could go through with the experiment' "(in Mauss 1975, 351).

This suggests that introducing this <u>possibility</u> in this community might benefit first-time admissions who might be less likely to receive usual and customary treatments for the diagnosis they receive. Thus, some persons hospitalized might be spared high dosage levels of psychiatric medications, and/or medications by injection, and/or accorded early release.

PART IV

Conclusions of Study

CHAPTER 9

MENTAL HEALTH CONSUMER EXPERIENCE REVEALED: TOWARD A THEORY OF SOCIAL VULNERABILITY STATES

Introduction

In preceding chapters, I have explored many facets of the mental health consumer experience. I have focused on the intersection of consumers' experience with traditional mental health care system offerings (treatments and programs), and their participation in one mental health consumer-run organization, Alternatives By Consumers (ABC). I contend that the nature of their experiences with the organization is affected by their investment of time and energy in organizational work. These investments subsequently affect their embrace of the organization as a supportive community, their definitions of self within the organization, and comprehension of their problems and their peers' problems in managing community living situations. It has also affected their vantage point on system "change issues." People participating in this research project from ABC increase our knowledge about the complexities of their personal, organizational and system-related difficulties. Their observations lead us to a different understanding of the ways in which the bureaucratic structure and practices of providers in the mental health care system affect consumers of mental health care in positive and negative fashion.

The grounded theory of mental health consumerism that these collected data illuminate begins the discussion in this chapter. This theory also connects to a broader understanding of everyday social life, a "substantive general theory" as described by Glaser (1978, 52). Both theories are informed by a central concept, 'social vulnerability states,' a primary feature of social disadvantage that became salient during data analyses.

Grounded Theory of Mental Health Consumerism

Whatever its etiology, experienced social vulnerability (e.g., strangeness or loss of self felt or manifested through various accommodation mechanisms[1] like mania, depression, withdrawal, hallucinations, suicide attempts) creates an enhanced need for a definition of the situation that provides meaning and/or explanation for what I describe as a social vulnerability state.

A social vulnerability state is the essential exemplar for disturbance in social and/or self identity that creates a need for meaning. Social vulnerability is the core element, the essence, of what the phenomena of this study exemplify.

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[1] These accommodation mechanisms represent "examples of the class of possible phenomena" that might describe a vulnerability state. See Chapter 3, "Methods and Methodology," for discussion of phenomenological tenets incorporated in this research design.

The concept embodies the invariant quality of mental health consumer experience. Social vulnerability is revealed as a shared condition; individual situations vary, but the essence of this condition for consumers of mental health care does not. Social vulnerability is a concept which captures "those conditions every variant must meet as an example or manifestation of a specific class of possibilities" (Rogers 1983, 72). Informed by a phenomenological understanding, the concept is an essential exemplar of the variations in mental health consumers' experiences represented in this study.

Definitions of the situation in early childhood caretaking settings provide individuals with a definition of their emerging self. Most consumers in this research sample have had early and unrelieved experiences with social vulnerability in their families. Childhood is a time of social vulnerability for human beings; they are dependent on adults and incompetent to provide for their own needs. Wineman (1984) defends this conception in the passage below:

> Parents [and/or other adult guardians] wield enormous power over almost every aspect of a child's life. They can subject their children to psychological degradation or humiliation, double binds, sexual repression, arbitrary or demeaning punishments, all with minimal possibilities for countervailing influences from other adults who might play a significant caretaking or nurturing role. Parents have the further right and power to create all sorts of expectations and demands shaping the child's interests, ambitions, performance, and sense of self--regardless of the child's intrinsic interests, aptitudes, and capacity for self-definition.
>
> A common-sense distinction between legitimate parental authority... and excessive or illegitimate authority is not culturally promoted or widely practiced. ... The domination of children by their parents is shaped, reinforced, and compounded by the isolation of the nuclear family and the division of roles and responsibilities within it (Wineman 1984, 123-124).

In this conceptualization, we see that the structure of the family ensures childhood vulnerability. The effect of this structural property is compounded by the structural properties of families in this society, i.e., generally isolated, stratified by division of labor and responsibility, and subject to self-contained definitions of appropriate treatment, care, or valuing of children within the units.

In these early years, people taking part in this research project received "definitions of the situation" from others that communicated to them aspects of their competence (e.g., "you can't do anything right") and social worth (e.g., "Who do you think you are? You're a nobody;" "you will amount to nothing;" "you're like a weed in the flower garden"). Social practices of family members or other caretakers (e.g., sexual abuse, physical abuse, psychological cruelty or neglect[1]) reinforced messages about definitions of situation/self. Other experiences within the family exacerbated this early experience of social vulnerability (e.g., loss of parent/caretaker through divorce or death; impoverished living conditions).

Unrelieved social vulnerability motivates behavior that will lessen experiences of individual discomfort accompanying this state. Experienced social vulnerability evokes a range of responses. As experienced social vulnerability continued unabated (i.e., growing older within the family units did not change the messages nor allow them power to change or resist

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[1] All consumers in this research sample reported abuse and/or neglect in one or several of these areas.

them), individuals accommodated this social vulnerability in a variety of ways (withdrawal, tantrums, development of "delusions," self-harmful acts, exit to living on the streets). Their accommodation to the experienced and continuing social vulnerability state assumed specific form over time, so that some people learned to approach social interaction in characteristic ways (e.g., with dread, fear or withdrawal) and/or also learned to approach conflict within themselves in characteristic ways (e.g., harm to self temporarily alleviates anxiety or terror).[1]

Accommodation forms employed by consumers in this sample were both proactive and reactive to early childhood situations. The child is not a passive entity upon which definitions of situation or self are unilaterally imposed. Hence, accommodation forms are reactive, in the sense they that attempt to purge undesirable, frightening, or anxiety-provoking feelings or cognitions about self or situation. For example, staying in a bedroom during family reunions allays feelings of "I don't fit in my family; I'm a misfit" because the issue is not raised by interacting with family members. Accommodation forms are also proactive in the sense that they affirm the dominant sense of self experienced. Illustrations for this conception might include: "I have control over my body--I can hurt it;" or "I have control over my world--in my

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[1] This was reported by several consumers in this sample. The dynamic is also supported in the literature. See, for example, Teixeira (1984).

fantasy world I am a king who governs." When accommodation forms are not troublesome, i.e., they "work" as intended by the individual and/or they achieve their purpose without severe disturbance to the individual or others in their immediate environment, they may be considered "in stasis." Under these conditions, the need for others' to define the situation or self is minimized.

If early behaviors motivated by social vulnerability no longer relieve discomfort, individuals develop other behaviors to relieve discomfort. When accommodation mechanisms fail to achieve their original purpose, i.e., "relief" from personal or social conflicts or "affirmation" of self-control, this increases feelings of social vulnerability. In turn, these feelings elicit a need for "better" accommodation mechanisms. The characteristic forms the accommodations once took become more complex and/or more serious; for example, withdrawal becomes total, or self-harming acts edge closer to suicide attempts. Newly created or intensified forms of accommodation frequently cause more discomfort (e.g., fear, anxiety, emotional confusion) to the individual and/or come to the attention of others.

Individual (or manifested) discomfort motivates the individual (or others) to seek a definition of the situation that will give meaning to the behaviors and/or experienced discomfort. Intensity of discomfort in the face of this quandary intensifies the search for something--or someone--who can "explain" these events to the individual. This perception is based on data collected for this study. It is also informed by

Anthony Giddens' (1983) explication of "critical situation" (1983, p. 124-127).

Giddens defines a critical situation as:

> a set of circumstances which - for whatever reason - radically disrupts accustomed routines of daily life" (p. 124). The common elements involved in critical situations seem to be: ... that *radical disruption of routine* produces a sort of *corrosive effect upon customary behavior* of the actor, associated with the impact of anxiety or fear. The circumstance *brings about heightened suggestibility ... to the promptings of others;* the correlate of such suggestibility is regressive behavior. The *outcome of these is a new process of identification* ... more permanent in protracted critical situations *with an authority figure*" (Giddens 1983, p. 126). (Emphasis added.)

In my analyses, the "authority figure" represents the least vulnerable of the parties in interaction. Therefore, he or she can implement a preferred definition of the situation needed and embraced by the person experiencing extreme vulnerability.

Intensity of discomfort appears directly related to the subsequent search for "definition of the situation" that is meaningful to the individual (and/or to those involved with the individual). Persons engaged in this seeking are susceptible to definitions of the situation provided by others who are not experiencing extreme social vulnerability. Thus, vulnerable individuals become more susceptible to influence from any source, but particularly from mental health professionals, accorded "expertise" by virtue of formal training, <u>and</u> other consumers at ABC, accorded "expertise" by virtue of experiential knowledge, who are not as vulnerable as they are.

Length of exposure and intensity of involvement with those providing definitions of situation or self increases the *likelihood that "new" messages will be accepted.* This explains why length of time in face-to-face encounters[1] and degree of involvement (i.e., intensity of investment of time and energy) with either mental health care system personnel and/or ABC consumers are significant factors in subsequent developments. These conceptual relationships are graphically illustrated in Figure 2, below.

Vulnerability State	High need for definition		Low need for definition	
	+ invest.	- invest.	+ invest.	- investment
Extreme	Acceptance expected	Acceptance unlikely	N/A	N/A
Accommodated (stasis)	N/A	N/A	Acceptance possible	Acceptance unlikely
Resolved	N/A	N/A	Acceptance unlikely	Acceptance not expected

Figure 2: Intersection of Vulnerability State, Definitional Need, and Level of Involvement with Definer

Figure 2 posits four likely outcomes (acceptance expected; acceptance possible; acceptance unlikely; and acceptance not expected) with respect to acceptance of others' definition of self and/or situation depending on social vulnerability state

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[1] Giddens' conceptualization of the interrelationships between time, space, and social change informs this discussion. "...Any patterns of interaction that exist are situated in time; only when examined over time do they form "patterns" at all..." Additionally, "In face to face interaction, the presence of others is a major source of information utilised in the production [and reproduction] of social encounters" (1983, 202-203).

(which in turn effects a high or low need for definition), and extent of investment of time (i.e., substantial [+] or inconsequential [-]) in face-to-face encounter with the "definer." In resolved or accommodated social vulnerability states, there is a low need for others' definition; during extreme social vulnerability states, the need for definition is high. The likelihood of acceptance of others' definitions depends on the investment of time in interaction with the definer: the higher the time investment, the more likely a new definition (of self or situation) will be accepted. When accommodation forms are in stasis (i.e., not causing consequential discomfort to the individual), there is a possibility that a new definition of self or situation would be accepted if the investment of time in interaction were great, but this is less likely than when the need for definition is greater (as when people experience extreme social vulnerability). The "not applicable" cells in this table indicate the relationship between lack of social vulnerability and lack of need for definition and its inverse relation.

The diagnosis becomes the definition of the situation and self for persons experiencing social vulnerability who consult mental health professionals. In this society, professionals in the field of mental health are socially constructed/normatively defined as experts in areas of personal discomfiture. When psychiatrists or other mental health professionals are consulted for expert advice about overcoming personal frustration, confusion, lack of social ease, or concern over puzzling compulsive behaviors, etc., their definition of the situation for the involved person is stated as a diagnosis.

Diagnoses (whether broad, as in "mentally ill," or by category, as "manic-depressive") are received when people are most vulnerable and most in need of explanation of their situations. Therefore, belief in assigned diagnostic categories is most entrenched and least subject to critical reflection.[1] Diagnoses "explain" (i.e., account for) the discomfort to the involved individual and others in their social network; provides membership for the diagnosed person in a group of "similars;" and allows individuals to objectify their situation (i.e., as a "manic depressive," I am not responsible for actions during periods of mania).

Because the diagnosis imbues the situation with meaning, people act to maintain the constancy of their situation. Assignment of diagnostic category (and concomitant calculation of prognosis for the "illness") can be seen as a prophecy, where the diagnosed person fulfills the expectation ascribed to their "role" as "manic depressive," or more broadly as a "mental patient" or "mentally ill" person. Thus, received diagnoses can evoke a self-fulfilling prophecy.[2]

When the prognosis for recovery includes enduring diminished capacities, the diagnosis also serves as a prophecy of

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1.These data are examined in the "Diagnosis issues" section of Chapter 8.

2."The concept was developed by R.K. Merton, based on W.I. Thomas' statement: 'If men [sic] define situations as real, they are real in their consequences.' This is also known as the Thomas theorem" (in Theodorson and Theodorson 1969, 375).

future life chances (e.g., schizophrenics can only hope to become secretaries, not executives or professionals). This may also be incorporated into the self-fulfilling prophecy of the diagnosed person, who learns to expect that even if competitive employment is attained, a life-long "illness" _means_ that he or she will miss periods of work (e.g., during times of cyclical exacerbation of the "manic depressive illness").

An important feature of the diagnostic process is that providers have greater social power in treatment settings than consumers for a number of reasons. The reason most relevant for this discussion is because providers are not experiencing social vulnerability. Therefore, they can implement their definition of the situation, as a diagnosis, in the interaction. Providers are also less likely to be structurally vulnerable by virtue of gender, class, or color.[1] They are able to implement their definition, rather than impose it because the consumer _embraces_ the definition; the acceptance of the construct is not passive. During commitment proceedings, however, providers may impose their definition because they are accorded unilateral power to define by virtue of their "expert witness" status in the courtroom.

When I suggest that consumers embrace their diagnoses as definitions of self, I ground this perception in research data, but I also draw upon a specific conceptualization of action developed by critical theorists (e.g., Giddens 1979).

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[1] For discussion of the gender, class, and race affiliations of the majority of psychiatrists and other mental health professionals (white, middle-class males), see Hill (1983, pp. 238, 259).

Action is a continuous flow of conduct in time and space, impelled by people who could have acted otherwise, i.e., who choose to act in certain ways while excluding others. Knowledge about other choices for action can be conscious and/or unconscious. Intentionality is a *process*: motivation to act stems from both conscious and unconscious impulses. "But the unconscious, of course, can only be explored in relation to the conscious" (Giddens 1979, 58). Self-reflexive monitoring is the vehicle for exploration. However,

> It is not enough merely to distinguish between conscious and unconscious. It is important to differentiate two senses in which agents are knowledgeable about the social environments they constitute in and through their action--between discursive and practical consciousness (Giddens 1979, 31).

Giddens links motivations to actions through "accountability." "Discursive consciousness" allows actors to draw on what they know, or understand, about the social world to account for their action(s). However, this "by no means exhausts the connections between 'stocks of knowledge' and action" (Giddens 1979, 32). This is where 'practical consciousness' fits. "Practical consciousness draws on "tacit knowledge" that social agents have, but are unable to "formulate discursively." This refers to knowledge that we use to get around in the world--to know, without being able to say--the difference between using language and explicating its use in principle and rule applications.

Thus, as consumers embrace their diagnoses, they draw on what they know and understand about the social world to account for their actions ("discursive consciousness"). Their understanding of "mental illness" accounts for their actions abstractly; their how-to knowledge about living in a state of vulnerability ("practical consciousness") is explicated by the rendering of their personal diagnostic category because each category of diagnosis describes traits/accommodation mechanisms ("symptoms") which they manifest in behavior. They find that their own how-to "recipes" for coping cohere with others' recipes that are listed for a specific diagnostic category (e.g., "manic depressive"). Thus, *persons experiencing social vulnerability embrace the diagnosis because it accounts for their specific situation.*

In addition to the ready explanation a diagnosis provides, it also resonates with known definitions of "mental illness" and/or specific diagnostic traits provided by the social stock of knowledge which members of the collective are exposed to and have internalized[1] during childhood (and continuing) socialization.[a]

> Institutionalization of cultural patterns means ... internalization of the same patterns in the personality. Psychologically an internalized pattern is no longer an object of the situation. It is not possible to treat it as an instrumental means or condition. There is a specific model of cathectic integration of the actor's need dispositions with an internalized pattern. This fact has a fundamental methodological significance. It means that the orientation of "instrumental rationality" *cannot* be the attitude defining the actor's orientation to internalized patterns (Parsons [1953] in Della Fave 1980, 959-960).(Italics in the original.)

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[1] This process is interactive. Encountered social knowledge may be internalized (and beyond reflection) in some areas, but it is also created and changed by the act of living in the world and reflecting on (i.e., trying to make sense of) experiences.

Thus, once a value is internalized, it cannot be "removed" from consciousness nor can it be tapped into and used as a means to attain an instrumental end (i.e., rationality). It is not possible, on a conscious level, to know all that we have learned about "mental illness" or "mentally ill" people as members of this society; active reflection, which seeks to uncover unconscious and typified definitions of this "condition" which are salient must be pursued. (Habermas' comments on "Self-reflection as Science: Freud's Psychoanalytic Critique of Meaning" (1968, pp. 214-245) address the problems that arise when self-reflection is stymied by repressions or distortions of communications. Habermas suggests that in the reconstruction of life-history (through methodical self-reflection/science of psychoanalysis) a self-transformation process ensues, that reunites the self with the world and serves an "emancipatory interest.")

Within contemporary structures of the bureaucratic mental health care system and practices of its personnel, the diagnosis serves not only to define the situation to involved persons, but also as a guide to "usual and customary" treatments for the diagnosis.[1]

"Usual and customary" is language used in the insurance industry to determine reimbursement amounts for submitted health care claims. When applied to treatment practices, the terms indicate the national standard against which submitted

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[1] See Chapter 6, "Treatment experiences," for a review of these data.

expense claims are evaluated according to diagnosis, treatment, and testing received for a suspected condition.

Recently, the application of "usual and customary" treatments has been applied in malpractice cases against psychiatrists who have been sued because they did not prescribe major psychiatric drugs and/or because the "dosage of antipsychotic medication was inadequate and deviated from the standard of care"[1] for the rendered diagnosis. This reveals that the "usual and customary" treatments (i.e., administration of major psychiatric drugs) for diagnoses that involve psychotic features (e.g., schizophrenia) have become the legal "standard of care" against which deviations are measured. Thus, actors within the legal system cooperate in adding another layer of social control to prescription of these drugs: psychiatrists are liable to malpractice suits if they fail to prescribe them. As a result, in contemporary mental health care practice, when a person is labeled schizophrenic they are prescribed major tranquilizers; when a person is labeled manic depressive they are prescribed lithium, usually in addition to other tranquilizers. This was true for 14 of 15 persons in this research sample, all of whom were public mental health consumers.

This is not to deny the possibility that some public mental health consumers can avoid major psychiatric medications, even if diagnosed with a psychotic condition and/or a condition that can be labeled "chronic mental illness." It is

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[1] In *Mental Health Law News* Vol. 3 #10 October 1988, p. 2.

rare, however. Private consumers may have a slightly better chance to avoid immediate treatment with major psychiatric drugs for similar conditions because their choice of practitioners or hospitals is less constrained by economic situations. Private mental health care treatment options are also less constrained by bureaucratic mandates in public sector care.

For instance, psychoanalytic therapists, rarely employed by the public mental health care system, have argued that the treatment of choice for schizophrenia is psychoanalytic psychotherapy conducted by psychologists rather than psychiatrists (with respect to benefits and cost savings). The Karon and VandenBos (1981) study at Michigan State University determined greater effectiveness of psychologists' psychoanalytic therapy alone versus therapy with concomitant psychiatric drug use or drug use alone. One summary finding from this study serves to illustrate their point:

> ... the patients treated by psychologists via psychotherapy were only hospitalized an average of 7.2 days in the 2-year follow up group, as compared to 93.5 days for patients of psychiatrist psychotherapists [who prescribed medications for 10 of their 12 patients]... [and] 99.8 days for the medicated control group (Karon and VandenBos 1981, 452).

Most frequently, consumers of mental health care receive a number of different diagnoses and a number of different medications or other treatments. This finding (reported in Chapter 6) is best understood within the context of research which reveals the controversy behind constructs of "mental illness" and their categorical distinctions within the mental health care sector (e.g., Mirowsky and Ross 1989; Hill 1983; Miles 1988, 20; Wheaton et al. 1980; Levinson and York 1974; Ehrlich and Abraham-Magdano 1974; Szasz 1987; Chesler 1972; Mauss 1975, 351; Rosenhan 1973; Masson 1988; Lewontin, Rose and Kamin 1984, pp. 197-232; "Mental Health Letter," Vol. 3, no. 11, p. 3; Harding et al. 1987; Quitkin et al. 1980). It has also been documented that "usual and customary" treatments, e.g., medications, ECT, and less frequently psychosurgery, cause significant harm (e.g., Breggin 1983; Hill 1983; "Mental Health Law News," Oct. 1988, p. 3; Kane and Smith 1982; Jeste and Wyatt 1982; Baldessarini and Tarsy 1980; Fann et al. 1980; Schooler and Kane 1982; Brandon et al. 1971; Pryce and Edwards 1966; Zugibe 1980; Weinstein and Goldfield 1975; Weiner et al. 1980; von Hartitzsch et al. 1972; Tow 1955; Shopsin and Gershon 1975; Price and Levin 1978; Pickar and Davies 1978; Paulson 1959; Meerloo 1955; May 1959; Marrocco 1972; Kinross-Wright 1955; Ivnik 1979; Hartlage 1965; Cohen 1974; American Psychiatric Association 1980; Alarcon and Carney 1969; Agulnik et al. 1972).

Consumers reveal a lack of received information about such treatments which might otherwise allow them to provide informed consent to the treatments. This claim is grounded in data for this project.[1] Several consumers express an unquestioning acceptance of what they have been told about their

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[1] An extensive overview of consumers' understandings about their medications is provided in the 'Inpatient and outpatient psychiatric medications' section of Chapter 6, "Consumers' Treatment Experiences."

medications, even when their own experiences with the drugs contradict the information they have received about them from their providers.

Consumers' reliance on providers' claims about the benefits of major psychiatric drug use reflects the political and ideological processes which reify and perpetuate use of these drugs (see e.g., Hill 1983; Breggin 1983; Magaro et al. 1978; Chamberlin 1978; Warner 1985; Brown 1985; Szasz 1987). These processes are reinforced by professionals' disregard of consumers' communications about the actual effects of drugs prescribed to them (e.g., Sighn 1976, 191-196, reviewed in Chapter 2). Breggin (1983) cites relevant literature which exemplifies this claim:

> It is rare that the outright adversary relationship between the psychiatrist and his patient finds its way into the psychiatric literature. For one of the most honest descriptions of this relationship we are indebted to Lehmann (1970). The need for long-acting medications is particularly strong in psychiatry, according to Lehmann, because of the 'lack of motivation for treatment which is so often characteristic of the psychiatric patient...' *This resistance to treatment is*, in Lehmann's opinion, 'a *sign of mental illness*'....Psychiatrists believe that resistance is so wholly a matter of 'mental illness' that it doesn't matter if the patient resents being forcibly subjected to ... [chemical] therapy (Breggin 1983, 47-8). (Emphasis added.)

Anthony Giddens (1983, pp. 49-130) illuminates the role of social structural forces in perpetuating such conceptualizations in society. Practices informed by role prescriptions reproduce practices, and coalesce in a system of practice that becomes institutionalized (i.e., practices have spatial and temporal dimensions revealed in social institutions). Social institutions thus represent many layers (through time and space) of reproduced practices.

As mental health practitioners bestow diagnoses that appear to consumers as definitions of their situations and prescribe harmful treatments that consumers learn to define according to practitioner-received information, these practices become entrenched as 'standards of care' in the profession and legal system.[1] Thus, the provision of mental health care is as much an established institution as the experience of mental health care. This is revealed in similarities of world views shared by professionals (Magaro et al. 1978, 170-173) and in different but commonly shared world views of consumers (e.g., professionals are experts who define situations by diagnosing people who are scared or confused; professionals will provide answers and/or offer protection through hospitalization and administration of drugs).

The professional's system of diagnosis thus becomes a closed social system, primarily informed by knowledge only from other professionals and/or from researchers in the field. Political gatekeepers of the field discount and/or fail to fund research not in keeping with the dominant and operationalized ideologies of mental health care. They are motivated by interests that are relevant to their social situation, economics and professionalism (e.g., cost effectiveness of psychotropic drug treatments; inadequacy of verbal therapies for

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[1] For one example of this with respect to diagnoses, see Mirowsky and Ross, "Psychiatric Diagnoses as Reified Measurement" *Journal of Health and Social Behavior*, Vol. 30 # 1 March 1989, pp. 11-25; 38-40.

working class and/or low income consumers).

> Professional researchers have become the gatekeepers of funds by appointment to the scientific boards of federal agencies funding research....[T]o this point researchers have themselves determined what research is supported. ...Caplan and Nelson (1974) .... see research in the same cultural boat as treatment, a means of supporting the dominant ideology. Thus psychological research commissioned by government may fulfill an overriding ideological goal by locating the problem within the group under study rather than outside it (in Magaro et al. 1978, 162-3).

Moreover, as revealed in the treatment histories of ABC consumers, definitions of the situation applied by professionals to consumers they treat are rarely altered by consumers' disclosures about treatment effects. Their voices are silenced. They do not contribute to the definition of the situation applied to them.

For example, diagnoses are based on personal interviews, but the power to implement a preferred diagnosis and treatment is accorded only to the professional. Negotiated definitions of the situation do not apply to admitting situations. This is not the only factor affecting an intake or outpatient situation, however: diagnoses are a crucial determinant for inpatient care allotments and/or physician fee payments from third party carriers. These structural properties of the system augment the interactional patterns through which diagnoses are determined.

When people are experiencing social vulnerability, this increases the likelihood that an offered definition of self will be accepted. As these definitions of self are perpetuated over time in treatment settings, consumers' ability to impose, implement, or even reflect on the received definition wanes.

Customarily, this experience is either unacknowledged by the professional or disclosure about it is discounted if broached by the individual in treatment. Unless broken, this pattern ensures that the institution of professional mental health practice will remain a closed social system.

Enter Consumers: Changing Patterns of Interaction

To change the nature of the closed social system that imposes definitions/diagnoses and treatments on consumers, consumers must enter the dialogue. Their input reveals that their social vulnerability and susceptibility to influence from others' definitions of them are directly related. Through this process, the conceptualization of power is widened. *During interaction, power is achieved by implementing a definition of situation or self for a person experiencing social vulnerability.*

The work of the Alternatives By Consumers organization reveals that consumers can benefit from exposure to peers' definition of their situation which does not prophesy a bleak, unchanging future but suggests that social interaction based on belief that consumers can help each other grow and recover is well-founded. They can look at others involved at ABC who are recovering and find the belief validated. The initial identification with others who have shared their treatment experiences can give way to modeling their behaviors after other consumers who have accepted the peer-to-peer definition of the situation which includes conceptualizing all consumers as people who are capable.

Provision of new definitions of situation or self from peers in a supportive community may attenuate experienced social vulnerability. In the act of changing the received definition of the situation from professionals (i.e., self as "mental patient"), they begin the passage to empowerment. Empowered people reclaim abilities to direct their lives, and their futures. This power has not yet been seized by all participants at the organization; the constructions of self as "consumer advocate" or "transitional advocate" remain tied to the organizational setting.

Attenuation of social vulnerability in a supportive community may lead to situated empowerment and/or to eventual mental health. For people who commit to the organization, identify with its social philosophy, and invest of themselves in its endeavors, it is the Alternatives By Consumers' community that sustains their construction of self as empowered. <u>Within the ABC organization,</u> empowered people frequently assume an advocate position vis-a-vis other consumers who come to the organization during times of intense social vulnerability. Their advocacy work reinforces the emerging self (i.e., changed definition of self) and the help they extend to others helps them as well.[1] In these interactions, their experience of extreme social vulnerability abates. For some persons, high levels of involvement with the ABC organization and meaningful connection to the consumer community it affords, have been

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[1] See Chapter 8, "ABC Experiences," for a review of these data.

needed stepping stones to later restoration of mental health.

Were the vantage point of the vulnerable mental health consumer included as part of a dialogue about an appropriate definition of the situation for them, the closed social system of professionalist dominance would open. The ideologies that justify the mental health system "as is" become subject to reflection by virtue of new knowledge. Upon reflection, the harmful assumptions made about consumers by virtue of their diagnoses (or the more broadly applied "mentally ill" label) may change. The possibilities for this unfolding scenario have begun. Changed typifications[b] of consumers and providers, and altered relationships between them are facilitated by the inclusion of ABC as a funded, consumer-run organization within the Michigan Department of Mental Health bureaucracy.

ABC consumers demonstrate that all are capable when believed to be so; all can develop meaningful social relationships given opportunity and motivation to do so; and all can take new risks when support for the endeavor is perceived.[1] Whether or not they engage in these activities is related to the amount of time they are exposed to these positive beliefs and supports, their investment of time and energy in pursuit of these activities, and the length of time they were <u>denied</u> exposure to different beliefs and supports, through choice, circumstance or limited knowledge of alternatives.

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[1] This finding is supported by relevant literature as well. See, for example, Wethington and Kessler (1986, 78-89).

Social Vulnerability: Changing Mental Health Care Practices

If consumers engage in dialogue with professionals, the additional knowledge professionals gain will become a "new" piece of the social stock of knowledge, from which they draw subsequent definitions of the situation irrevocably altered by this exposure.[1] As the practices of professionals and the institution of mental health care change, so too does the collective comprehension of "mental patients" change. The social stock of knowledge which provides the referent for understanding people in vulnerable states is thus broadened.

Certain extreme social vulnerability states (e.g., psychosis, apathy, lack of self-awareness) will preclude some people from entering the dialogue about appropriate definition of the situation with professionals offering mental health care services. While peers may be able to help others through periods of great social vulnerability, there will be occasions when people who are vulnerable need protection (e.g., when suicide is planned) and/or people in their immediate environments need protection from them (e.g., social vulnerability may spark homicidal rage directed toward others). At these times, people with substantial knowledge about intense feeling states will likely be sought out to intervene and/or assist people seeking to help a vulnerable person (e.g., professionals, consumers, family members of consumers, etc.). Whoever is deemed able to provide expert advice, even _if_ informed by new

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1.The complexities of eliciting professionals' motivation to listen to consumers, and learn from them, is explored in the following pages.

knowledge offered by others in similar social vulnerability states, is still ascribed more power than the vulnerable person (and/or the worried "others" who have sought help for someone else) to define the situation and prescribe treatment or intervention.

Thus, the problem of power inequalities between persons who are more and less vulnerable still obtains, whether the circumstance is neighbor-to-neighbor, consumer-to-consumer or consumer-to-professional consultation. *Differential experience of social vulnerability creates inequity in interaction.* In consideration of this, an understanding of the "personal is political" is also needed to alter dynamics between people with differential access to power (i.e., power to implement a certain definition of the situation).

In interactions between people of unequal power, there is opportunity to impose, rather than implement, a favored definition of the situation. Feminist theory reveals that private interactions carry political import (i.e., the personal is political).[1] Because practices reproduce practices, and by extension, non-parity interactions reproduce non-parity interactions, other factors must be identified to motivate embrace of interactions that will result in equality between the parties. A partial list may include: revelations of physical and/or psychic damage caused by routine practices; illumination of the larger social costs for such practices; identifi-

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[1] See, e.g., Evelyn Fox Keller (1983, 15-21).

cation of persons who can alter such practices and/or be held accountable for their continuance and costs; and separation of social practices which may benefit socially vulnerable people from medical treatments which obscure important details of non-organic conditions.

At the mental health care system level, personnel can become motivated to arrive at definitions of the situations (i.e., diagnoses and treatments) for the population of mental health consumers that are the <u>least</u> invasive and the <u>least</u> damaging to subsequent life chances by including "social cost" accounting in their financial accounting systems.[1] Political gatekeepers who protect economic interests of professionals can be enlightened as to the ramifications of previous "usual and customary treatments."

When drugs that damage brains are routinely prescribed, their physical and psychological effects prevent return to full employment. The more people who are thus prevented from pursuing competitive employment the larger the drain on the general "social programs/welfare" fund. The drain on the general fund is complemented by the loss of potential tax revenues working consumers might otherwise have contributed. As the "usual and customary" treatments continue, people treated in this way do not recover (i.e., their social vulnerability state continues unrelieved) and continually draw on social resources. As others enter the system of care and

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[1] For a comprehensive explanation of the "social cost" accounting concept see, e.g., David Smith "The Public Balance Sheet," in McGuigan and Shaeffer (eds.) (1978).

receive similar treatments, numbers of persons sustained at subsistence levels increases, accruing further loss of revenues and further necessary expenditures. Alternatively, people who are unable to work competitively may turn to non-legal modes of income procurement (e.g., black market drug sales, theft, extortion, etc.).

As long as system administrators and practitioners do not perceive their connection to this dynamic, nor suffer from its continuance (i.e., they remain unaccountable for the outcome of therapy, drug regimes, etc. and continue to receive salary and/or fees for their "treatment"), there will be little motivation to alter the workings or structure of the system. The "fault," in system personnel eyes, lies with the individual and/or their "illness."[c] If medical treatments for diagnosed non-organic conditions do not alleviate it, it is only because the real "cure" has not yet been found.[d] Medical research continues to be funded (rewarded) at high levels in search of the drugs or mechanical interventions that will cure.[e] The trap of the medical conceptualization of "mental illness" is thus revealed.[f]

> The medicalization of deviant behavior is part of a larger phenomenon that is prevalent in our society, the individualization of social problems. We tend to look for causes and solutions to complex social problems in the individual rather than in the social system. This view resembles Ryan's notion of 'blaming the victim'; seeing the causes of the problem in individuals rather than in the society where they live (Conrad [1978] in Schwartz and Kart [eds.] 1978, 77).

When non-organic conditions are labeled "mental illness," consumers of this study report that stigma and discrimination coincide with others' knowledge of the psychiatric label they bear. The pejorative connotations need not apply, however, if the conditions that people labeled "mentally ill" manifest are perceived as one among many possible social vulnerability states. In this event, the need to medicalize the condition in order to understand it dissolves. Instead, the focus is steered toward negotiating a definition of this particular social vulnerability which makes sense to the person seeking advice (or on whose behalf advice is sought) and also to the person consulted.

As the construct "mental patient" fades from collective view and is replaced with "a person attempting to resolve a state of social vulnerability," then community and society can gain from the return of the recovered person to their midst. Their return does not need to be feared by community residents or families; since the vulnerable do not suffer from a condition understood only by professionals, others may identify with and/or intuitively understand the situation. Hence, future contributions from the recovered person can be <u>expected,</u> through tax revenues created from their employment, through their ability to lead the community to lucrative or beneficial ventures, through their art work or music, etc.. These expectations can likewise act as a prophecy for the involved person who meets expectations to recover as easily as they met expectations to relapse due to the nature of their "illness."

I argue that this scenario is possible. This does not mean that exceptions to this possible outcome are not to be expected, however. It is highly unlikely that after 800 years of stigmatizing people thought to be "mentally ill" that changing the conceptualization of the problem will result in wide-spread community citizens' acceptance of people formerly perceived as dangerous, unpredictable, irrational, etc.. I argue that this is a necessary first step, however. It may not prevent people who look vulnerable to others from being victimized; it may not prevent people whose creativity at times is unbounded from being ridiculed; but unless the contemporary vision of non-organic "mental illness," and persons thought to be suffering from it change, it will not happen at all.

In sum, it is in the collective benefit to alter the definition of the situation provided to (or involuntarily imposed on) consumers of mental health care. People participating in the organization Alternatives By Consumers have demonstrated one inexpensive and successful route to assisting others in changing their received definitions of situation and self when provided opportunity to do so. It is time, and well past time, that the collective shares in this responsibility to carry the torch forward.

Facilitating development of consumer-run organizations through allocation of social program funds requested of legislators is one avenue; reflecting on the social and political ramifications of interactions when one person's definition of the situation is implemented for (or imposed on) another, more vulnerable person, is another avenue. (This necessarily applies to consumers at ABC, of course, as they seek to help peers in more vulnerable situations than their own.) There are many more avenues for "torch-carrying" available to individuals, organizations, unions or associations, state and federal department personnel who can chose to reassess the "knowledge" they have received about the conditions labeled "mental illness."

Wineman's (1984, 158ff) concept of "negative consciousness" may be heuristic in this regard. His discussion of this concept illuminates benefits that can be realized by the dominated as well as those who dominate if the relationship is altered:

> Negative consciousness starts with the simple notion that equal relations can be experienced as more rewarding than top-down relations ... It is only from the position of an equal--in terms of power, status, and full regard for other people's humanity--that it is possible to experience mutuality, to fully develop emotional capabilities, to have the most stimulating intellectual exchanges, to become deeply rooted in a shared social existence. ...*In our society, equality which is experienced as positive and rewarding does not happen to people--it has to be actively created. And it is exactly in the realm of personal politics and everyday life that this can begin to happen* (Wineman 1984, 189-190).

Reassessment with consideration of new knowledge may impel different sorts of policy and program decisions by those in positions that affect them; it can similarly change interaction patterns in face-to-face encounters.

Because grounded theory arises from the analysis of human behavior, and not in specific individuals or units of individuals (such as ABC) observed and consulted during research, it has broad applicability to the shared human condition. In the next section, I take the insights developed in this substantive area and apply them to a wide range of social experiences. That is, I attempt to provide the beginnings of what Glaser, one of the "founders" of grounded theory methodology, describes as a "general substantive theory" (1978, 52). In this application, I hope to contribute to the development of new theory in sociology.

Toward a Theory of Social Vulnerability States

Social vulnerability to others' definition of the situation is created and/or structured. Structural social vulnerability states include (but are not limited to): categories of age, the very young and the very old; gender; class; social or organizational status; and health. Created social vulnerability occurs during crises, e.g., personal or psychological; social; economic; physical, and/or when departures from mainstream ideologies or norms (e.g., homosexual orientation, radical political orientations) become known to others. Regardless of cause, social vulnerability states diminish power of individuals to implement their perceived "definition of the situation." Diminished power in this regard provokes a search for "definition of the situation" that will make sense of the social vulnerability state experienced.

There is a reciprocally reinforcing relationship between structural social vulnerability and created social vulnerability. That is, if someone occupies a structural social vulnerability state by virtue of age, gender or economic situation, the effect of a created social vulnerability state intensifies the loss of power potential. Examples of created vulnerability states include (but are not limited to): serious physical deterioration, loss of housing, or denial of eligible promotion. Structural positions reflecting more than one categorical social vulnerability state (e.g., poor and physically impaired) increases the likelihood that social vulnerability will be experienced in social interaction. If someone does <u>not</u> currently occupy a position of structural vulnerability (e.g., a professionally employed white male), but social vulnerability is created through certain events (e.g., loss of job), the subsequent diminution of power to implement a definition of the situation may create a structural social vulnerability (e.g., loss of class position or status).

Constructions of reality that maintain received negative definitions of self, others, and/or situations of either, represent accommodations to social vulnerability states that inform subsequent social interactions. Examples of this concept include: constructions of self as "incapable;" constructions of social relationships as "dangerous," or "mortifying;" constructions of "whites," "blacks," or "foreigners" as "unknown dangers," etc.. Over time, accommodations to felt social vulnerability assume specific behavioral, cognitive, psychological, and social form. These manifestations might include (but are not limited to): development of behaviors that are self-effacing or attention-seeking; intellectual development characterized by rigid or highly creative thought; psychological development characterized by compulsive or obsessive behaviors; or social relationships characterized by guardedness or obsequiousness in interaction.

When the form the accommodation to social vulnerability assumes becomes troublesome to self or others, i.e., it no longer imparts meaning to the experience, need for a definition of the situation that will return meaning to specific experiences motivates the individual or others (to whom the individual's form of accommodation has become troublesome) to seek definition or resolution of the troubling condition.

If the troubling condition is circumstantial, experts may be sought who can alleviate or attenuate the circumstance. For instance, if accommodations to impoverished living situations cause individual discomfort and/or social ridicule, experts on public assistance may be consulted. Bureaucrats in positions to authorize or allocate resources provide one example of an expert, as seen _in relation to_ the person experiencing social vulnerability. Similarly, loss of a promotion for which one is eligible may motivate the individual to seek help from experts in Affirmative Action procedures; loss of housing may motivate seniors to contact experts in a Department of Social Services to resolve the dilemma. In these instances, appeals to officials of a bureaucratic system can be seen as appeals to alter the definition of the individual's situation through changing the circumstance of that situation.

When these consultations result in changing the circumstance that evoked accommodation forms causing individual discomfort and/or social ridicule from others, the experience of social vulnerability is attenuated and/or extinguished. The meaning of personal accommodations to the circumstance is understood _in this context_: the circumstance "explains" the accommodation forms assumed and/or the social ridicule experienced to the individual. In effect, the changed circumstance implements a definition of the situation that is meaningful to the person involved. The experts have agreed to this definition tacitly, through allocation of resources that change the circumstance.

Alternatively, the search for meaningful definition of the situation may be abandoned in favor of acquiescence to a received definition of the situation and/or by achieving a non-troublesome stasis in the individual's preferred accommodation form. That is, the individual may attenuate felt vulnerability by avoiding situations that evoke it; and/or by developing friendships or relationships only with persons who share their cognitive, social, or psychological orientations. In situations where characteristic accommodation forms are no longer problematic to self or others, the need to find a meaningful definition of self or situation becomes less intense.

However, if the individual's power to implement a definition of the situation is not restored through recovery or resolution, the search for a meaningful "definition of the situation" continues. For example, if none of the experts consulted has helped the individual understand his or her own forms of accommodation to the experience of poverty, and/or the conditions of impoverished daily life remains painful, other professional experts may be sought for consultation.

Another interaction pattern, especially relevant to this discussion, can characterize failed attempts at resolving social vulnerability when individuals seek help with circumstances thought to be causing it. If the experts consulted define the situation as the individual's fault, changing the circumstance may not alleviate feelings of vulnerability. Seeking relief from poverty may be perceived by officials in the bureaucratic system as "laziness," caused by the individual's lack of industry (and/or in other stereotypic ways). This may be communicated to the involved person in a variety of ways during interactions with the bureaucrat: through voice inflection, phrasing of questions, interrupting the individual's communications, etc. Thus, *ascribed, negative characteristics of self become the definition of the situation for persons experiencing social vulnerability who seek needed resources from authorities who impose a definition of situation.*

Power to implement a new definition of the situation is realized only in interaction.[1] Interaction occurs between persons who occupy certain social positions vis-a-vis each other (e.g., peer relations, superordinate-subordinate relations). When one party of the interaction is more vulnerable than the other, the likelihood that the more powerful party

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[1] This idea is given credence by study data: the most vociferous and/or harmful behavioral manifestations routinely occur when people are alone. Without others who can "argue against" the self-generated (or compelled) definition of the situation and self being acted on, the individual will pursue the accommodation form "chosen" or impelled.

will define the situation <u>and</u> the less powerful party will accept it is enhanced.

People with power to implement a definition of the situation are supported by peers who define situations for others in similar ways. They are also supported by people who accept the definition of the situation that they offer. Thus, if people seeking help with circumstances accept the definition of the situation as their own fault, and/or lack ability to implement a different definition of the situation because they are less powerful than the "definer," the definition of the situation presented by the bureaucrat becomes an imposed definition of the situation. In situations where people are dependent on "definers" for resources as well, continued need for the resource may evoke accommodation forms specific to that context. Frustrated abilities to implement a different definition of the situation may give way to behaviors that facilitate continuing receipt of needed resources, e.g., deference to those in authority. Thus, several layers of structural vulnerability may add to the social vulnerability that originally motivated need to search for a meaningful definition of the situation.

As the imposed definition of self continues over time, it may be unwittingly or consciously accepted. A typical construction by the involved individual in this instance might become: 'If it weren't my fault, I would be off public assistance by now.' As this occurs, the individual's ability to reflect on the received definition of self lessens. If similar, categorical definitions of persons in similar circumstance pervade the social milieu (e.g., "welfare cheaters"), this also affects individual abilities to reflect on the accuracy of such definitions.

Those providing expert advice draw on the social stock of knowledge that explains (and/or conceptualizes) such situations to members of the society. The social stock of knowledge does not contain the vantage point of the vulnerable: it only contains the typifications (i.e., stereotypes) of the vulnerable. The definition of the situation provided by the experts is as much informed and bounded by this knowledge as the received definition of the situation is.

Definition of situations in topical or "spatial" areas (e.g., public assistance benefits, Affirmative Action specialists, child guidance experts) evoke specific social practices according to the situation presented. Social practices are differentiated by the social position of the people in interaction. That is, social practices engaged in with peers (e.g., professional to professional) differ from those between superordinates and subordinates (e.g., bureaucrats and clients).

Social practices informed by role prescriptions that attend certain social positions reproduce practices over time and constitute a social system (e.g., of capitalism, professionalism, racism, sexism). Social systems that are supported and accepted over time become social institutions, i.e., spatially defined practices with a temporal dimension. Definitions of the situations that apply to social institutions are therefore deeply embedded through spatial and temporal dimensions in specific socio-cultural contexts. Constructions concerning the nature of clients, the nature of professionals, or the nature of bureaucracy represent examples of deeply embedded definitions in this society.

Socio-cultural contexts (e.g., capitalist societies; patriarchal societies) enhance certain definitions of the situation according to the power of positioned actors to implement favored definitions. Certain positioned actors, through achievement or ascription of status, have differential access to resources which are allocated and/or authorized according to established and/or institutional definitions of the situation.[1] Because power to implement definitions is the reserve of the non-vulnerable, resources are allocated or authorized to those who are more vulnerable and less powerful according to needs perceived by those meting out the allocations. Actors with more power than others also have facilitated access to resources as well as strategic maneuverability vis-a-vis allocation or authorization of resources.

Strategies used to determine resource authorization or allocation include inducements, e.g., cooptative strategies, and coercion, e.g., repressive strategies. In practice, strategies may represent a mixture of these two dominant modes as well as others not subsumed by either concept, such as cooperation. When coercion is used, parties to the interaction are not given equal voice. One voice is silenced; one voice is

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[1] This is elaborated in Giddens (1983, 96-130).

heard. When inducements are used as strategy, parties to the interaction are still not in parity, but the interaction is necessarily more complex because an offer by the definer needs to be responded to--either rejected or accepted; both voices must speak.[1] Parity situations, which might be characterized by cooperation, for instance, do not arise when one party holds greater power to define a situation.

Social Vulnerability: Informing Social Change

To change these process dynamics, and/or to achieve parity between parties in interaction, the non-vulnerable powerful must have reason/motivation to listen to the other party's definition of the situation. Efforts to include the vantage point of socially vulnerable persons in the operations of social institutions can be facilitated by consciously attending to, for example, "social cost" accounting, and raising awareness of the societal damage incurred by routine practices of sexism, racism, classism, etc.. As the social costs of routine practices become widely known, social prudence may guide those who define situations for others away from structurally invasive or physically damaging practices as a first resort. In their stead, emphasis will be on practices that are cooperative, and effectively rehabilitative.

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[1] This dynamic, which necessitates verbal exchange, has been especially significant to the development of the Alternatives By Consumers organization (see Chapter 5, "Case Study, Part II" for details). The benefits of this structured interaction as a requirement of funding speak in favor of continuing funding for any community action group, but especially for consumer-run mental health organizations.

Social responses will span a continuum of reactive and proactive practices in this regard. For instance, the social cost of defining situations of poverty as an individual's fault may become salient as a factor precluding individual desire to subsequently enrollment in school or job training programs. As this becomes known, interactional practices among bureaucrats and clients may receive special attention to achieve change in customary patterns. This social response is predicated on reaction to new knowledge provided by persons who are socially vulnerable. Similarly, structural disincentives built into the public assistance system (e.g., lack of child care precludes women receiving AFDC from leaving home for work or school) will be revealed as impeding attainment of autonomy[1] and/or fiscal independence, and damaging. The proactive social response will entail restructuring of the public assistance system.

Negotiated definitions of the situation change all subsequent patterns of interaction. On an interpersonal level, no unilateral definition of the situation exists, so it must be arrived at mutually. This alters customary practices formerly characterized by imposed definitions from one to the other party in interaction. On an organizational or institutional level, negotiated definitions may change customary practices and perceptions of persons formerly defined only according to professionals' perspective. In turn, changes in practice and

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[1] For purposes of this discussion, autonomy may be viewed as a resolved vulnerability state.

perception may affect decision-making authorities and/or strategies for allocation of resources.

Negotiated definitions are thus characterized by a certain fluidity (subject to the vantage points of those in interaction). They are dynamic. However, they may or may not be consensual, depending on the quality of social vulnerability state, e.g., "extreme" or "accommodated, and in stasis." When extreme, definitions may be mutually arrived at, but would be less likely to be consensual.

There will be times when "professional experts" must define a situation for people who are socially vulnerable and/or pose a threat to their own (or others') safety. But the social stock of knowledge from which experts will draw information to be applied to specific individual situations can be enlarged by including the vantage point of the vulnerable. Were this to occur, experts in certain areas (e.g., public assistance system operations, criminologists) would have a different appreciation of the need to engage in on-going dialogue with categorical representatives of social vulnerability in which their expertise lies (e.g., public assistance recipients, "criminals," children). They become attuned to the social costs of previous "usual and customary" definitions and treatments applied based on the definitions.

The only way that the social stock of knowledge which informs those who define situations for others will expand is through the input of those previously denied voice in the dialogue. Thus, those defined by others or self as socially vulnerable, must be included in dialogues which define their situations.

As entering consumers change the discourse and practices in the sociology of mental health, mutually negotiated definitions of the situation applied to others who are socially vulnerable can change the discourse and practices of the larger collective. In our discourse and our practices, we must learn to serve the ends of "emancipatory interest" for <u>all</u> members of the collective.

<u>Conclusions: Summary of Research Theories</u>

The components of the grounded theory of mental health consumerism and the beginnings of a general substantive theory of social vulnerability states are summarized below.

<u>The Grounded Theory of Mental Health Consumerism</u>

Major premise: A social vulnerability state is the essential exemplar for disturbance in social and/or self identity that creates a need for meaning.

Minor premises:

Definitions of the situation in early childhood caretaking settings provide individuals with a definition of their emerging self.

Unrelieved social vulnerability motivates behavior that will lessen experiences of individual discomfort accompanying this state.

If early behaviors motivated by social vulnerability no longer relieve discomfort, individuals develop other behaviors to relieve discomfort.

Individual (or manifested) discomfort motivates the individual (or others) to seek a definition of the situation that will give meaning to the behaviors and/or the experienced discomfort.

Intensity of discomfort appears directly related to the subsequent search for "definition of the situation" that is meaningful to the individual (and/or to those involved with the individual).

Length of exposure and intensity of involvement with those providing definitions of situation or self increases the likelihood that "new" messages will be accepted.

The diagnosis becomes the definition of the situation and self for persons experiencing social vulnerability who consult mental health professionals.

Persons experiencing social vulnerability embrace the diagnosis because it accounts for their specific situation.

During interaction, power is achieved by implementing a definition of situation or self for a person experiencing social vulnerability. (Differential experience of social vulnerability creates inequity in interaction.)

Provision of new definitions of situation or self from peers in a supportive community may attenuate experienced social vulnerability.

Conclusion: Attenuation of social vulnerability in a supportive community may lead to situated empowerment and/or to restored mental health.

Toward a General Substantive Theory: Social Vulnerability States

Major premise: Social vulnerability to others' definition of the situation is created and/or structured.

Minor premises:

There is a reciprocally reinforcing relationship between structural social vulnerability and created social vulnerability.

The ascribed, negative characteristics of self become the definition of the situation for persons experiencing social vulnerability who seek needed resources from authorities who impose a definition of situation.

As the imposed definition of self continues over time, it may be unwittingly or consciously accepted.

Constructions of reality that maintain received negative definitions of self, others, and/or situations of either, represent accommodations to social vulnerability states that inform subsequent social interactions.

Socio-cultural contexts (e.g., capitalist societies; patriarchal societies) enhance certain definitions of the situation according to the power of positioned actors to implement favored definitions.

Negotiated definitions of the situation change all subsequent patterns of interaction.

Conclusion: The only way that the social stock of knowledge which informs those who define situations for others will expand is through the input of those previously denied voice in the dialogue.

In the next and concluding chapter, I examine policy and program implications in light of these emergent theories, with attention to the change suggestions broached by mental health consumers (previously detailed in Chapter 8). From this foundation, I also propose areas for further research and highlight the contributions of this study to the discipline of sociology and to prospects for social change.

CHAPTER END NOTES

(a)"Socialisation should be understood as an element of the continuity of social reproduction--of the inherent temporality of social process--rather than as just referring to the temporality of the personality formation of the child" (Giddens 1983, p. 128). *"The unfolding of childhood is not time elapsing just for the child*: it is time elapsing for its parental figures, and for all other members of society; the socialisation involved is not simply for the child, but of the parents and others with whom the child is in contact, and whose conduct is influenced by the child just as the latter's is by theirs in the continuity of interaction ... children "create parents" as well as parents creating children. ... Socialisation is thus most appropriately regarded not as the 'incorporation of the child into society,' but as the *succession of the generations* (Giddens 1983, 130). (Emphasis in the original). It is in this sense that I apply the concept "socialization" to this discussion.

(b)"The reality of everyday life contains typificatory schemes in terms of which others are apprehended and "dealt with" in face-to-face encounters...typifications ongoingly affect...interaction...[they] are reciprocal. ...Unless challenged, the typifications will hold until further notice and determine...actions in the situation" (Berger and Luckmann 1967, 31).

(c)For instance, unsuccessful outcomes (i.e., the individual remains in a vulnerable state) are routinely described as the "patient's fault": they are "resistant." For literature which supports this idea (most of which is based on Freud's psychoanalytic conceptualizations), see, e.g., Strean (1985); Karon (1981, pp. 143-4, 226-228). For critical reviews of this concept, see, e.g., Masson (1988), Magaro et al. (1978), Hill (1983). Alternatively, "patients" may be described as "resistant" when they fail to "comply" with major psychiatric drug regimes (see, e.g., Breggin 1983, 34-38).

(d)"The notion of cure assumes that a person's internal psychic structure can be fixed, so that regardless of the social environment, s/he can adjust and function effectively. With great irony, the ideology of curing holds out the ideal goal of total independence from emotional support at the same time that the practice of professional helping creates a structure of dependence" (Wineman 1984, 80).

(e)For a stunning portrayal of this practice in medical research on schizophrenia, see Lewontin, Rose and Kamin *Not in Our Genes: Biology, Ideology, and Human Nature,* Chapter 8: "Schizophrenia: The clash of determinisms" (1984, 233-294).

(f)Ivan Illich has also documented this aspect of social life in *Medical Nemesis* (London: Calder & Boyars, 1975).

CHAPTER 10

CONCLUSIONS, CONTRIBUTIONS, AND RECOMMENDATIONS: CHANGING MENTAL HEALTH CARE POLICY AND PRACTICES

Introduction

The emergence of a grounded theory of mental health consumerism and mental health system "change suggestions" offered by consumers participating in the Alternatives By Consumers (ABC) organization provide initial direction for recommendations concerning mental health system policies and practices. The emergent "theory of social vulnerability states" indicates that resolution of experienced social vulnerability and inclusion in a supportive community are focal needs. The change suggestions offered by consumers reflect these needs, but they also highlight several practices of current mental health care (especially with regard to hospitalization procedures) that are not rehabilitative nor responsive to the situations consumers encounter.

One important caveat should be noted before policy recommendations are explored, however: practices reproduce the current mental health system, not policy. While this insight is informed by the work of a critical theorist (Anthony Giddens 1983), it is given credence by actual developments in the field of mental health policy and practice.

These developments will be explored in the following pages, considered in light of research findings and literature which underscores the effect of professional organization on the practices of personnel in the mental health system. Following this exploration, policy recommendations will be offered that address issues raised.

In the concluding sections of this chapter, I outline the contributions of this study and areas for future research in light of the policy and practice change recommendations.

Treatment Practices as Mental Health Policy

It will be recalled that most of the mental health system change suggestions offered by consumers (e.g., need for different hospital admission and discharge practices; need for incentive in rehabilitation programs; need for improved quality in interactions between practitioners and consumers) revealed discrepancies between policy and practice. The implicit plea in their commentary was for the system to operate as intended, rather than as it does in actuality. The practices of the system were generally seen as failing to meet intended goals, i.e., restoration of mental health for consumers.

By ABC consumers' reports, traditional practices of the system have been maintained over time (e.g., excessive use of psychiatric medications; incarceration in state hospitals; violation of consumers' rights to refuse treatment; ineffective aftercare programs; refusal of or inadequate emergency treatment), despite a policy which mandated, as a contingency for federal funding, a 5-tier community-based care plan to be made accessible through local Community Mental Health Centers (i.e., emergency treatment; inpatient community hospital care; outpatient psychotherapy and after-care; partial hospitalization "rehabilitation" and/or pre-vocational programs; and consultation and education aimed at preventing onset of "mental illness"). ABC consumers' experiences articulated by this research sample support a summary overview of the CMHC effectiveness offered by one social policy analyst in the field: "It seems clear that the community mental health center program has done best in those endeavors most similar to traditional clinical service activities [drug administration, hospitalization]... The areas of greatest failure have been those most removed from traditional training and practice [outpatient support and rehabilitation programs]" (Bloom 1984, 51).

The people participating in the Alternatives By Consumers organization are consumers specifically targeted by mental health system planners as those most likely to benefit from practices of deinstitutionalization and development of Community Mental Health Centers' outpatient care schemes (Bassuk and Gerson 1978). That is, most ABC consumers are people labeled "severely" or "chronically mentally ill." And yet, the treatments of choice identified by Community Mental Health Centers' spokespersons (in Bloom 1984) are designed to be most beneficial for persons who are <u>not</u> suffering from long-term conditions. The disjuncture between the stated 'policy' and the actual practices of the system are revealed in descriptions of services and identification of those thought to benefit from them.

"Three innovative service approaches are associated with the community mental health movement--planned short-term therapy, crisis intervention, and mental health consultation" (Bloom 1984, 56). The first two services are briefly described below; they provide an important comparison point for policy and practice suggestions discussed later in this chapter. (CMHCs mental health consultation services predominantly serve practitioners and other direct care workers, and are tangential to this discussion.)

Community Mental Health Centers' Treatment Services

In his discussion of planned short-term therapy, Bloom (1984, 57-102) notes that this service approach developed in response to increased numbers of people seeking help at Community Mental Health Centers (CMHCs) and a "growing dissatisfaction with the gradual lengthening of traditional psychodynamic treatment" (Bloom 1984, 57). He defines this service approach as "short-term treatment that is intended to accomplish a set of therapeutic objectives within a sharply limited time frame. ... [Its] efficiency and economy rationale ... is stressed most notably by persons in the public sector" (Bloom 1984, 58).

In Bloom's subsequent review of developers and proponents of planned short-term therapies, the description of clients most likely to benefit from this service approach depart dramatically from the profile of consumers labeled "severely mentally ill." Identified objectives for treatment are routinely posed in terms of increasing abilities to "function" in the community.

Bellak and Small (1965) identify the goal of brief psychotherapy "... is limited to the removal of or amelioration of specific symptoms.... Brief psychotherapy [i.e., 5-6 sessions] seeks to help a client continue to function, so that nature can continue its work of healing...." (Bellak and Small [1965] in Bloom 1984, 64).

Malan (1963, 1976) considers that the goals of brief psychotherapy can be attained in 10 to 40 sessions. Of his research, Bloom notes:

> Because successful brief therapy depends on client characteristics, Malan and his group have gone to considerable lengths to specify the criteria for acceptance or rejection of applicants. ...A client with any of the following clinical characteristics is rejected (because these conditions are often severe and disabling): serious suicide attempts, drug addiction, "convinced" homosexuality, long-term hospitalization, more than one course of electroconvulsive therapy, chronic obsessional symptoms, ... and gross destructive or self-destructive acting out (Malan [1976, 67-68] in Bloom 1984, 66).

From this description, it appears that no ABC consumer from this project (nor most of those using ABC) would be accepted for such therapy.

Wolberg (1965) identifies "abbreviated therapeutic goals" for short-term therapy. The goals identified include: symptom relief, restoration of prior level of functioning, and beginning recognition of character traits that prevent a more satisfying life adjustment (in Bloom 1984, 68).

> Wolberg proposes that conditions [best suited to] short-term therapy are those in which the goal is rapid restoration of homeostasis in an acute neurotic disorder, resolution of an acute upset in a chronic personality disorder, or personality reconstruction in persons unsuited for long-term therapy (Bloom 1984, 69).

Those conditions least suited to this technique include client need for prolonged support, constant and unrestrainable anxiety, and uncontrollable acting-out tendencies. It is again apparent that nearly all ABC consumers participating in this project (or the organization) would fall outside the identified boundaries of those most likely to benefit from this approach.

Other time-limited therapies reviewed by Bloom (e.g., Le win's [1970] brief confrontive therapy; Sifneos's [1972] anxiety-provoking short-term psychotherapy; Farrelly and Brandsma's [1974] provocative therapy; and Bloom's own focused single-session therapy [1981]) identify similar goals for brief therapy and similar client profiles. Dominant goals are to restore functioning and achieve symptomatic relief; clients best served are people experiencing acute upset. This leads some analysts to suggest that:

> The mental health establishment ... sees its role as facilitating the reduction of deviance [from value norms], but it also allocates its services primarily to those clients with a high likelihood of reintegrating into the dominant value structure.... This is ... the mechanism behind [Goldstein's 1971] "YAVIS" composite therapy patient, one who is young, attractive, verbal, intelligent, and successful (Magaro et al. 1978, 172).

In a review of literature specific to CMHCs 'crisis intervention' services (Bloom 1984, 103-154), the allocation of emergency services appears to support the claim Magaro and

Goldstein levy above. Namely, by definition and design, crisis intervention services are best suited for the anticipated short-term client. Bloom suggests 3 criteria used by community mental health workers to justify emphasis in this service area: most community citizens will undergo crises at some time in their lives; persons in crisis are thought to be "unusually receptive to clinical intervention;" and effective treatment during crisis may reduce the incidence of psychiatric disability (Bloom 1984, 103-4).

> Several studies have examined the effectiveness of crisis intervention as a function of (1) immediacy of intervention and (2) the client's adaptability. [There is] some evidence that immediacy is influential ... in terms of characteristics of the client, such as anxiety or other symptomatology. There is some evidence that characteristics of the client before the crisis are among the best prognosticators of crisis outcome (Bloom 1984, 153).

These reviews support a central claim of this research project and the reports of ABC consumers participating in it. Despite formal policy statements to the contrary, contemporary mental health care provided by the network of CMHCs has neither attended to the needs presented by the 'deinstitutionalized' "mental patient" nor to consumers deemed to be "chronically mentally ill." Collected data for this project, largely reflecting mental health care experiences in the 1980s, continue to support the 1978 observation about the effect of deinstitutionalization practice and CMHCs service provisions: "The resident population of large mental hospitals has been reduced by two-thirds in 20 years, but chronic patients are being discharged to a lonely existence in hostile communities without adequate care" (Bassuk and Gerson 1978, 46).

Study Findings as a Guide for Change Efforts

Despite their lack of fit to profiles of people most likely to benefit from contemporary CMHC mental health care services, ABC consumers valued their outpatient psychotherapy experiences in the mental health system as situations where they were nurtured to various degrees. (These stand in contrast to their predominantly negative hospitalization experiences.) However, no person in the sample spoke of psychotherapy as a key vehicle for their development of positive self-image nor as the medium through which they learned to develop positive, reciprocal social relationships, although three persons referred to therapy as a support needed to undertake new activities involving personal risk (e.g., accepting new employment). (It is noteworthy as a commentary on the lower standard of public mental health care that two of these three persons were in psychotherapy with private sector, not public system, practitioners.) The nurturance afforded by psychotherapy contributed to their perceptions of available social support, but was not cited as an inducement to form other social relationships of quality and/or intimacy. (This does not exclude that possibility, of course; it simply appears not to be as salient as the nurturing received.)

The distinction I make between psychotherapy as a situation of nurturance versus one of intimacy is informed by the work of Lillian Rubin (1983), who asserts that:

> Nurturance is not intimacy. It may be connected to intimacy, may even sometimes be the result of it, but the two are distinct and separate phenomena. Nurturance is caretaking. Intimacy is some kind of reciprocal expression of

> feeling and thought, not out of fear or dependent need, but out of a wish to know another's inner life and to be able to share one's own. Nurturance can be used as a defense against intimacy in a relationship--a cover to confuse both self and other, to screen the fact that it doesn't exist. It can be used manipulatively--as a way to stay in control, as a way to bind another ... (Rubin 1983, 90).

Therapy experiences afforded ABC consumers participating in this research project comfort, but were not depicted as empowering per se. In this instance, the policy guiding practices of the care system, i.e., provision of psychotherapy which provides relief from "symptoms" and restores a level of adequate social functioning, may have been partially fulfilled. However, these policy objectives assume that the client seeking service is acutely distressed; abatement of distress does not address the enduring nature of coping problems experienced by most people at ABC.

Additionally, a broad overview of mental health system practices reveal departures from the bureaucracy's "guiding plan" developed in 1955 through the mid-1960s. As Charles Kiesler notes (1982):

> In spite of a national policy of deinstitutionalization and outpatient care, the episodic rate of hospitalizing mental patients has increased in the last 20 years ... Of the funds spent on mental health in the United States, 70% goes to hospital care (Kiesler 1982, 349).

Thus, despite deinstitutionalization and Community Mental Health Centers' provision of outpatient and supportive care, and policy intimations that hospitalization was to be deemphasized and avoided whenever possible, the practice of the system belies its plan: hospital admissions and readmissions have increased, despite a reduction in the average length of a hospital stay.[1] Through the <u>practice</u> of "associating the CMHC with physicians and hospitals, the <u>policy</u> seems to assert that emotional disorders are primarily biological and require ... medical treatment, ... including hospitalization" (Bloom 1984, 33; emphasis added). The inertia of standard practices maintain the system's tacit policy, public commentary concerning explicit policy (deinstitutionalization, community outpatient emphasis) to the contrary.

Another feature distinguishing actual practice departures from formalized policy among mental health professionals is their differential application of formal training/knowledge in the workaday world. As Eliot Freidson (1986) cogently argues, the practices of professionals in this regard vary by their position in the system (e.g., practitioners, administrators, teacher-researchers, and professional elites who hold leadership roles in professional associations, appear as expert witnesses to Congress and in civil commitment hearings, etc.).

This feature makes it difficult to know how professionals work with consumers unless the consumers are consulted. Practitioners apply formal knowledge according to the exigency of the situation they face with particular consumers. Thus, consumers' treatment experiences, reviewed in preceding pages, are the closest we can come to knowing how formal knowledge and training is--and is not--actually applied. This anticipates a significant contribution of this research project.

Short of first-hand study, only documents produced by the

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[1] See Brown (1985, 74-76), for a discussion of this finding.

> rank-and-file practitioners and their clients can show us the ultimate transformation by which a considerably modified, even contrary, version of formal knowledge is finally expressed in living practice (Freidson 1986, 229).

The kind of formal knowledge practitioners at any level (e.g., nurses, psychiatric technicians, psychotherapists and/or psychiatrists) have had matters less than how they apply, or eschew, their formal education in practice. "Formal knowledge can be applied to human affairs and practical action only by making arbitrary and selective decisions" (Freidson 1986, 215).

Beyond decision-making in the context of situational exigencies, practitioners must also attend to the rules communicated to them by administrators. "Administrators are concerned with having the practitioners' work carried out in such a way as to satisfy the political and economic forces on which their organization depends" (Freidson 1986, 212). Although practitioners' decisions govern the allocation of resources in specific treatment situations, it is administrators who "have the power to allocate what resources are available to the organization and to specify the needs and problems the practitioners are supposed to serve" (Freidson 1986, 214).

Administrators, in turn, are subject to rules generated by teacher-researchers in schools where formal knowledge is institutionalized. The latter division within the profession is not considered as one which has access to any direct power over events in the professional workplace, "though their work may form the basis for both organizational rules and decisions at work of its individual practitioners" (Freidson 1986, 214).

Thus, administrators and teacher-researchers within the profession of mental health are the farthest removed from treatment situations, and may yet be powerful, if "silent," partners to practitioners.

There is another division that Freidson notes within the ranks of any profession, whose occupants he distinguishes from the "ordinary members of the professions--academics, practitioners, and workaday administrators" (Freidson 1986, 214). These members of the professions, leaders of professional associations and elite practitioners, administrators and academics, serve as formal advisors and expert witnesses to those with political decision-making powers,

> ... by drafting legislation, by influencing the formulation of the administrative rules that implement legislation, and by formulating the product, personnel and procedural standards to be employed in serving what have been defined as public needs (Freidson 1986, 214).

In consideration of the characteristics of professions outlined by Freidson (1986), research findings from this project, and other researcher's reflections on the operations of the mental health system (e.g., Kiesler 1982), it can be argued that practices of mental health professionals have determined the nature of the system, not the policy that allegedly guides it. Moreover, the practices to which consumers react and/or respond are affected by professionals' subjective and objective considerations as well. The latter include political and economic forces affecting professional elites' dictates which subsequently affect decisions made by teacher-researchers, administrators and practitioners. It is <u>not</u> evident that formal education nor formal policy routinely guides the work of practitioners involved in interactions with consumers, although either factor might contribute to situational decisions practitioners must make (e.g., to prescribe major psychiatric drugs, to hospitalize, to mandate attendance in a rehabilitation program). It is therefore necessary to focus on changing the practices of the system which are known to damage consumers, and to attempt revision or change in other practices that have proven to be ineffective in empowering consumers.

Changing Policy through Changing Practices

Successful accomplishment of three essential tasks are posited below as end-goals for the mental health system. Efforts at changing specific practices within the system need to be informed by attention to these objectives. First, mental health consumers need assistance in resolving their social vulnerability states. Secondly, they need to locate a source which provides an empowering definition of situation/self that fulfills the need evoked by their social vulnerability--and one that they can embrace from a parity position. Thirdly, consumers need opportunity to become affiliated with a supportive community.

In practice, professionals to whom consumers turn for assistance in resolving social vulnerability may operate in ways which may or may not benefit individual consumers (e.g., via non-parity or "blame the victim" interactions and/or damaging treatment prescriptions); they may not be guided by tenets of their formal training or knowledge (which is sometimes a benefit to consumers); and they are likely to adhere to administrative rules which affect practitioner-consumer relationships (e.g., all non-working hours' contact is prohibited) which ensure their own continued employment in the bureaucracy, whether or not this is beneficial to consumers in their care.

This research project has shown that one available source to consumers seeking resolution of continuing social vulnerability is the consumer-run organization, Alternatives By Consumers (ABC), and the supportive community it provides. Funding has allowed the organization continuity over time, contributing to its coalescence as a community. Within the community, participants offer each other redefinitions of situation/self that counteract insidious messages communicated in traditional mental health care treatment settings. For consumers who invest significant amounts of time and embrace the possibilities of self- and other-change that ABC work affords, the redefinitional process in the context of the ABC community has positively affected the quality of their daily lives, the development of meaningful, reciprocal relationships with other people (mostly peers), and for some, the development of a critical viewpoint toward the offerings of the mental health system.

Whether or not consumers at ABC construct a self-identity within the ABC community that can be characterized as "consumer advocate" appears related to time and investment level in pursuing ABC activities, but also to the depth with which they have previously defined themselves as "mentally ill" and/or "a mental patient." This latter finding appears to be affected by the quality of early family experiences, the length of time that they have received mental health services, the degree to which they developed an inpatient identity (e.g., "a light bulb thief")[1], the degree to which this inpatient identity was rewarded by attention from hospital staff and/or outpatient therapists, and the amount of monetary support they received to continue their "mental patient identity" (i.e., number of years receiving disability benefits and level of benefit).

Data from this project also indicate that several different categories of consumers may be identified <u>within</u> the population segment of consumers labeled "chronically mentally ill."[2] Some consumers express little difficulty in embracing a peers-only community. They are represented by ABC consumers who became regular volunteers following initial contact with the organization, and continue to maintain this level of involvement and/or go on to become paid staff members. Other consumers initially embrace the advocacy work emphasis of ABC and become highly involved in these pursuits. However, as time passes, they decrease contact with the organization, falling to a level of involvement characterized by "cyclical volunteers." All ABC consumers in this latter cohort have maintained at least a moderate level of involvement with the

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[1] See Chapter 6, "Treatment Experiences; inpatient behaviors" section for a review of these data.

[2] These data are reviewed in Chapter 7, "ABC Experiences."

organization despite their investment of time and energy in non-ABC activities (e.g., school, pursuit of employment, starting a new family). People who initially become involved with ABC at a moderate level tend to remain at that level, which is also true for consumers referred to the organization by providers who maintain a low level of involvement _if_ their peers do not encourage further participation in the ABC community. People who are referred by providers _and_ receive encouragement from peers to become further involved subsequently become more involved.

These findings speak to the need for increased peer-to-peer intervention in operations of the traditional mental health care system. They also indicate the need to increase levels of funding for consumer-run alternative service programs, to accommodate consumers who realize situated empowerment at a consumer-run organization. Additional funding would enhance possibilities for volunteers to become paid staff members and simultaneously sever their dependency on income tied to continuing psychiatric disability (i.e., SSI or SSD).

Increased levels of funding would also allow development of additional services that consumers might appropriately offer to their peers. Additional services might be geared toward consumers who have not realized empowerment through connection to the ABC community. Examples include: residential settings that are staffed by paid consumers (or former consumers) who have ready access to consultations with mental health professionals on an as needed basis; and/or drop-in programs that include some structured and challenging activities that might involve persons who do not socialize at the center and prefer to spend time pursuing passive activities provided there (e.g., watching television, listening to music, reading magazines).

These ideas may seem to violate the tenet of "consumers can do for each other," in that professionals are on-call at the residential setting and structured activities preclude opportunity for participants to develop their own agenda of activities. However, this research has shown that the connection to mental health professionals is a very important source of perceived support. Providing access to contact in a residential setting may reassure consumer staff as well as consumer residents that support remains available during the new and risky undertaking. Provision of structured activities at the drop-in acknowledges the broad dimensions of the consumer population that peer organizations seek to serve.

To assume that all consumers will benefit from an unstructured program unwittingly denies the realities consumers also know: some people do not benefit in such situations. If developing genuine alternatives to traditional mental health care is the objective for consumer-run organizations, it would be wise to avoid the same assumptions that cause so much difficulty in the mental health system, i.e., that the nature of mental health consumers is known and addressed by services provided. It is apparent that what ABC currently provides does benefit many consumers, and some benefit significantly. But to move beyond a situated empowerment, and be able to internalize new strengths that will reclaim abilities to define personal situations regardless of setting, may be the broader vision that developing consumer-run organizations will want to address in the future.

Other suggestions for changing and improving practices in a consumer-run organization appear below. They draw on findings from this study and relevant research reviewed in preceding chapters. Important objectives to achieve in future operations of the organization include:

-Stimulating discussion of social variables affecting consumers' situations (race, class, gender, nationality, current psychiatric label), toward increasing awareness of factors that contribute to coping difficulties that are not caused by individual deficiencies, etc.

-Assessing decision-making patterns of the organization to ensure that elements of paternalism, sexism, rac ism, classism, ethnocentrism, and prejudice against non-heterosexual orientations are not embodied in the work of the organization. Additionally, stimulate discussion of ways in which organization may support treatments that are dangerous for consumers (e.g., by refusing to take a position on treatment) and ways in which advocacy efforts can complement other efforts by system-change supporters in the community.

-Stimulating discussion of effects of treatment modalities prescribed by caretakers, exploring alternatives, risks involved in current treatments, and compile information useful to consumers making treatment decisions.

-Compiling names of people willing to be consulted for tips on successful withdrawal from psychiatric medications and making this list available to interested consumers.

Over and above these specific suggestions, a central finding of this study should be paramount in endeavors to reform the traditional care system, consumer-run organizations, and the structures of the political economy that perpetuate social practices that are damaging to many citizens. Community is a crucial vehicle for maintaining, restoring or developing a sense of well-being. We have seen that for some, the ABC community is a means to empowerment. At the very least, the ABC community has been a means to comfort and a sense of security. In a society beset by social problems that reflect the waning sense of community in family units, neighborhoods, rural areas and even college campuses, the idea that community is critical to the future well-being of society as a whole is underscored. Efforts to stimulate social change in the larger society can be well-informed by the achievements of mental health consumers devoted to this task.

It was also found that since ABC supports the workings of the system as is (whether or not its members intend to), consumers hired by ABC, and/or those who offer their full-time volunteer services to the organization, do not necessarily have to redefine themselves as "advocates" to continue employment there. While the work of ABC contributes to the empowerment of some consumers within the organization, its work also allows some involved consumers to maintain a primary identity in terms of "mental patient." When ABC staff or volunteers advocate with consumers who extol certain treatments as helpful (e.g., drugs or ECT), the organization's philosophy of "gentle justice" upholds the individual's right to that treatment, precluding challenge to the system or practitioner concerning the treatment itself. When consumers accept treatments offered and ABC supports these decisions, the organization assumes the stance of deferring to professional judgments concerning "appropriate" mental health care treatments. Thus, ABC accommodates "mental patients" _and_ "advocates."

Taken together, the practices of system personnel and Alternatives By Consumers' active participants contribute to maintaining the traditional system which accords greater power to define situations (e.g., what constitutes appropriate treatment) to professionals versus consumers. The innovative program inaugurated by Michigan legislators as funding for consumer-run "alternatives" (through the conduit of the Michigan Department of Mental Health) thus supports the system status quo at the same time that it allows some "corrective" for the damage in stunted potentialities accorded by the routine practices of the system. Because the practices of system personnel and its innovative augment program, ABC, have not yet attained the explicit goals of the system (i.e., restoration of mental health, particularly for people labeled "severely mentally ill") through traditional treatment and/or alternatives to it, two interrelated areas suggest strategies for changing practices at ABC and within the system which will affect treatment outcomes for individual consumers. In broad terms, these strategic areas are exposure and accountability.

Changing Practices: An Exposure Strategy

It is crucial that the actual practices of the system be exposed. This exposure would allow scrutiny of system practices from many vantage points. Especially important would be the vantage point of persons not bound to decision-making according to dominant economic and political forces impinging on mental health professionals, its elite professional associations and advisors. As relevant literature suggests and data reveal, the actual practices of professionals in mental health care can only be known by consulting with the consumers of mental health services. Until and unless the practices of the system are exposed, and the outcomes of routine treatments are known, the public will be mislead by discussion of policy and attendant problems with its implementation that imply practices of the system are guided by its policies.

Another crucial component of exposure as a strategy for system transformation is to publicize widely the amassed research which documents the damage of "usual and customary treatments" in the system of mental health care. It is plausible that many sectors of the society might advocate for mental health treatments of "functional mental disorders" which do not result in brain damage, as treatments with major psychiatric drugs and electroconvulsive therapy do. Moreover, were this critical research recognized as integral to the "normal science" paradigm (of which it clearly is a part) instead of depicting it as a radical, atheoretical "attack" upon the integrity of the system or individual practitioners[a], potentially significant players on the scene of change, Alternatives By Consumers (and groups like it), might be able or willing to take an organizational stance against such treatments without risking loss of funding or good relationships with system personnel. Most importantly, individual consumers would have access to enough information about such treatments to make an informed choice about them.

Exposure in this area would also necessarily transform many of the practices of inpatient care. When psychiatric medications are no longer presented as a panacea to "behavioral problems" that the staff must address, and there is a system-wide interest --and support--for seeking alternatives to its use, hospitalization experiences would be qualitatively different. The first resort during times of patient upset (especially true for public mental health consumers) would no longer be seclusion, and/or a "take-down" which includes forced medication by injection and restraint. Additionally, if consumers refused their medications during hospitalizations, a confrontation with staff might no longer be the guaranteed next step if alternatives to drugging are explored and valued as a treatment objective.

Inpatient therapists, who have counseled some of the ABC consumers to believe that medications will allow them to "manage" their "life-long illnesses," would have to develop or rekindle their awareness of non-invasive alternatives they may (or may not) have been schooled in formally. Staff frustration at abandonment (and/or severe curtailment) of "usual and customary" modes of control on inpatient units might impel desire for and/or development of in-service training sessions which would focus on non-invasive alternatives (e.g., improving communications) to former treatments.

Exposure of the damage caused by invasive treatments might also stimulate deeper attention to the insights accorded by research in British and U.S. developmental psychiatry (e.g., Rutter 1985; Bowlby 1988); psychoanalytic psychology (e.g., Karon and VandenBos 1981; Teixeira 1988); and documented research between social relationships and physical health (e.g., House 1988). Deeper attention to the depth of accrued and/or unrelieved social vulnerability, which begins in childhood for most consumers, would be facilitated by such an approach. The loss of community represented by "loss" of the original family/community (through estrangement, ostracism, abuse, etc.) is a key feature of the unrelieved social vulnerability state. This conceptualization is informed by Robert Nisbet's definition of community:

> ... Community is a fusion of feeling and thought, of tradition and commitment, of membership and volition ... Its archetype, both historically and symbolically, is the family ... (Nisbet 1966, 47-8).

Recognizing situations that once precluded relief from social vulnerability; generated a negative definition of self; and became incorporated as "this is the way the world is" prototypes are important insights that allow possibilities for subsequent "correction" in the present.

Consumers are routinely deprived of opportunities, through circumscribed choice of public system therapists, to work with therapists guided by such an approach. Most frequently, practitioners are encouraged by administrators to pursue short-term therapies. ABC consumers in this research sample report that turn-over among therapists is frequent in the system, presenting another obstacle to continuity of longer-term therapy, even if possible. While some researchers contend that not all consumers will benefit from a developmental approach,[1] many consumers may benefit substantially by recognizing that past accommodations, needed in early situations, unwittingly impel similar accommodations to present-day interactions. Lacking an in-depth approach that seeks to unearth and/or eradicate old sources of current coping difficulties, consumers may learn to *function* in social settings but *freedom* from past emotional shackles may never be complete. (It is perhaps not coincidental that the goal of hospitalization, and the evaluation of its effectiveness, is posed in terms of "ability to function" after discharge. This same goal is identified as a treatment objective for short-term psychotherapy. Freedom--as ability to implement one's own definition of the situation--is neither a tacit nor explicit goal of outpatient or inpatient treatment. The latter objective is more commonly stated in terms of, e.g., "learning how

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[1] See Magaro (1978, 188-213) for compilation and critique of materials relevant to these issues.

to stay out of the hospital" (Martha Wright interview, 1987)).

While-application of a developmental approach could conceivably take more time than the currently in vogue "short term therapies," "crisis intervention techniques," and the like, it can easily be argued that the investment of time in treatment regimes for consumers deemed "severely mentally ill," which has stretched over decades in many cases, has not proved cost-effective nor resulted in recovery of mental health for consumers involved. Exposure of this latter finding can combat objections to the time-intensive treatment approaches suggested.[b] The cost-effectiveness for 10 years of intensive and restorative treatment versus 20-30 years (or more) of unsuccessful treatment is readily argued.

But there are political implications to long-term treatment that present an obstacle to its embrace that Karon (1986) notes. He reviews a study of patients bearing the psychiatric label 'schizophrenic' (Karon and VandenBos 1981) that revealed psychotherapy alone (versus psychotherapy and medications or medications alone) "led to an earlier discharge ... kept the patients out of the hospital ... improved their thought disorders ... [allowed] a more human life in a variety of ways ... and was cheaper in the long-run, saving nearly half the treatment costs over a 4 year period" (Karon 1986, 14). In this latter regard Karon states:

> Unfortunately, decision makers are not interested in saving money over four or more years. In that time there will be a different political administration, a different head of the hospital or of the department of the insurance company. The decision makers want to save money in this six months, and that is unfortunate (Karon 1986, 14).

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Combatting political self-interest which demands short-term effectiveness is a contentious problem. It is unlikely that this practice will change unless or until the voting public makes support of elected representatives contingent on their support for such a change in the mental health system.

To better inform the public, another important factor in an exposure strategy will be inclusion of sociological studies that reveal class, gender, race and nationality factors as variables (among others) which affect consumers' access to, and communications from, providers in individual situations (e.g., Roman and Trice 1974; Wethington and Kessler 1986; Gore and Mangione 1983; Newmann 1986; Jacobson 1986; Eaton, Jr. 1974). Critical sociologists may well represent part of the "revolutionary vanguard" that impel system change through exposure and cogent argument. Although there have been studies that focus on the support medical sociologists have offered to the establishment of medicine--and its practices--including mental health care (e.g., Gold 1977), by and large, sociologists of medicine are less constrained by economic and political considerations that may bias research conducted within the fields of psychiatry and psychology. (Relatively) free of professional interest in maintaining the system "as is," sociologists may have more leverage, and opportunity, to be critically reflexive about operations of the care system.

The benefit of including sociological studies as part of an exposure strategy can be seen comparatively in the U.S. sociocultural context. In other historical situations, when the bias of circumscribed access and differential treatment became public, the wheels of change slowly ground toward redress (e.g., during the Viet Nam War when it was found that young black men disproportionately were drafted and killed, the draft lottery was evoked; when race riots of the 1960s forced public attention to the societal discrimination levied against black persons as a group, Affirmative Action policies were developed and implemented). The exposure of the untoward practices in civil rights fueled change, despite continuing racism. It is plausible that exposure of untoward practices in the field of mental health might equally fuel change, despite continuing stigmatization of people labeled "mentally ill."

Exposure of system practices in the era of monumental federal deficits might also be posed to the public as an issue of fiscal responsibility. In the same way that the 1987 "Pentagon scandal" aroused the ire of the public who footed the bill for $200 toilet seats and $40 bolts, taxpayers need to know what the multi-million dollar mental health industry is returning to the society for its investment in this area. Kiesler's finding (1982, 349), introduced at the beginning of this discussion, might provide initial grist for the "change" mill. Seventy percent of all expenditures in public mental health systems go toward hospital care while the public is told that deinstitutionalization and community-based outpatient care are the policies their tax dollars support. Moreover, statistics reveal that many of the people receiving inpatient care are not first-time admissions; they are people whose previous hospitalizations were inadequate to their

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recovery needs and are returning to the only resource open to them. Tax payers may wish better return for their investment, if not honest disclosure about the actual workings of the system.

In a related vein, the public is entitled to know the social costs attendant to "business as usual" in the mental health system. The loss of human potential--or in management terminology, human capital--through death of incarcerated patients rarely achieves public attention. The magnitude of the tragedy is frightening. According to an internal Michigan Department of Mental Health report,[1] there is a 1 in 21 chance that a person hospitalized in a Michigan state mental hospital for one year or longer will die.[c] Three comparison points between previous mortality rates for Michigan inpatients and 1982 mortality rates indicate the problem is growing worse:

> 1. In 1950-1954, the inpatient death rate was 3.6% higher than that for the general population; in 1978-1981, <u>the death rate was 7.29% higher for inpatients</u> (death from any cause).
> 2. Age/sex ratios reveal that the risk of death is higher in the young person and highest for the young, white woman, whose death rate is <u>19 times higher</u> than that of the general population (death from any cause).
> 3. In 1950-1954, the suicide death rate was less than that of the general population; in 1978-1981 the suicide death rate for inpatients was <u>28 times higher</u> than that of the general population. (Emphasis added.)

Supporters of hospitalization as appropriate treatment may not wish to embrace this treatment modality when statistics reveal

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[1] Department of Mental Health, "Preliminary Report of Psychiatric Patient Mortality Rates," Prepared by Genice L. Rhodes, Director of Research and Evaluation Division, 11/3/82 (Internal publication). These data were also cited at a public meeting of the mental health appropriations committee at the Capitol on 11/6/83.

it may constitute a literal death sentence.

No less tragic is the "triple jeopardy" to society represented by ineffectual mental health "treatments," even if offered to outpatients. First, society loses through monetary support of persons who might otherwise be helped to recover; it loses potential tax revenues that might otherwise be generated by consumers returning to work; and it loses whatever other contribution empowered people might contribute to the general good (art, music, literature, inventions, etc.). This scenario may not be one that tax payers want to impel.

Exposure as a Bilateral Strategy

A strategy of exposure can also be used to publicize the benefits of funding consumer-run alternative programs such as ABC. In terms of fiscal responsibility to taxpayers, a clear case can be presented that indicates the cost-effectiveness of, for example, consumer-run drop-in centers versus the traditional Community Mental Health Centers' partial hospitalization programs (i.e., "day treatment" programs). Available figures[1] for one ABC satellite drop-in center (developed through the OUR Project) exemplify this trend:

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[1] As reported in the "Michigan Department of Mental Health Research and Evaluation Division Final Evaluation Report of: Consequential Minds, Inc. Drop-in Center Program" January 1989, 19-20. (Internal publication.)

Drop-in Center Program, 12 Months Operation

Unduplicated count, all patrons = 302 patrons
Center available for patron use = 2,314 hours
Total cost to State/one year = $ 25,000

Summary Calculations: (rounded to nearest dollar)

Expense to State/hour of operation = $ 11/hour
Expense to State/patron of center = $ 83/patron/year

CMH Partial Hospitalization Program, 12 Months Operation

Unduplicated count, all "cases" = 800 "cases"
Program available for use = 210 hours
Total cost to State/one year = $820,800

Summary Calculations: (rounded to nearest dollar)

Expense to State/hour of operation = $ 5/hour
Expense to State/"case" = $ 1,026/"case"/year

In this summary comparison, it can be seen that had the state increased the hours of operation for the partial hospitalization program ten times (thus nearing the hours of operation for the drop-in center), the cost per hour would approach $50 and the cost per "case" would exceed $10,000!

While there are obvious differences between these programs (e.g., structured activities and professional staffing patterns are present in CMH programs and absent at drop-in centers), such comparisons may be warranted if some shared program goals are considered. Both purport to serve the same population (i.e., people deemed "severely mentally ill") and both embrace the objectives of greater self-sufficiency and independence for participants. Moreover, when consumer Directors of such centers report that their employment at the

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center has eliminated the need for social security disability payments (true in this case, and for many other center Directors), the cost savings to the state may prove to be even more dramatic than outlined here.

More important would be exposure of the qualitative benefits that patrons of drop-in centers and ABC consumers report which include: improvement in self-esteem, increase in numbers of people named as friends, increase in social activities and opportunities, assistance with procuring entitlements from the care system that affect quality of living situations, and a sense of belonging or membership in the community that the centers' sustain. As evaluators of the program from the Michigan Department of Mental Health note:

> Probably the single best index of this type of project's value is what the consumers think about it. ...(T)he targeted consumers make wide use of the Center as a place to drop in and socialize and also as a problem-solving center where problems can be effectively dealt with by the on-site personnel. On the basis of utilization, cost, and consumer satisfaction measures then, the Drop-In Center has been one of the most successful consumer projects funded in the past year. ...[1]

Because such data may be perceived as biased due to the self-reporting element in centers' evaluations, it would also be important to disseminate the reports of consumer-run programs as professionally evaluated by local Community Mental Health Boards and/or the Michigan Department of Health. Unfortunately, many CMH Boards have <u>not</u> developed evaluation in-

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[1] This excerpt is from the Michigan Department of Mental Health "Final Evaluation Report: [Alternatives By Consumers] Drop-in Program," prepared by Chamberlain and Barker, Research and Evaluation Division, DMH, November 1986.

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struments for these programs that can allay charges of such bias. The Michigan Department of Mental Health comments on problems involved in evaluating such innovative projects:

> Another issue ... is the difficulty in evaluating the effectiveness and productivity of these projects. There are singly no standards and very little publicized experience vis-a-vis how these nontraditional programs should be operating.[1]

However, some evaluations of consumer-run centers by local Community Mental Health Boards may be effective in suggesting areas that indicate effectiveness of the programs. The early evaluation of the consumer-run ABC satellite center in Grand Rapids, for instance, suggested benefits to the community corresponding with the development of the drop-in center. It was written by the Planner/Contract Manager for Kent County Community Mental Health, the official liaison person from the CMH to the Grand Rapids drop-in center. The document addresses an initial 6-month evaluation conducted by the writer.

> The drop-in center has offered a compassionate and supportive alternative to the day homeless chronically mentally ill clients in the Kent County CMH system. Individuals who would otherwise be roaming the streets because their Adult Foster Care providers want them out of the house during the day are finding a safe and comforting alternative. ...
>
> The program is reaching out to a very high proportion of Black and Native American CMH clients, who are typically underserved by traditional CMH programs. ...
>
> This particular drop-in center is being run by and utilized by a group of consumers who would typically be described as severely chronically mentally ill. ... Some of these people were described as resistive to treatment or heavy users of crisis services.... Since the estab-

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1. In Mowbray et al. "Final Report, Consumer-run Alternative Services: Demonstration and Evaluation Projects, 1982-1984," Michigan DMH Internal Publication, November 1984, p. 28.

> lishment of the center, the use of crisis services by consumers using the drop-in center has declined. ...
>
> As a contract agency within the Kent Co. CMH system, the consumer run program has been very responsive to contract obligation issues such as financial and data reporting DMH required narrative reports and client satisfaction survey information. This...serves to strengthen the business relationship between the two organizations. ... [1]

The important areas to highlight in an 'exposure strategy' disseminating benefits of consumer-run programs might include those found to be salient in Grand Rapids: a) provision of a safe alternative for the day homeless mental health consumer; b) effective outreach to clients previously underserved by traditional mental health care offerings; c) decreased use of community crisis services by consumers participating in the alternative services program; and d) improved business relationships between official representatives of the mental health system and consumers operating the alternative service program.

As these results are disseminated, particular cadres of supporters may argue for increased funding for consumer-run programs because it increasingly appears as a "common sense" option. Supporters are likely to include: people critical of the current mental health system operations; people interested in fiscal responsibility; people arguing for increasing civil rights of incarcerated "mental patients"; people interested in augmenting availability of humane alternatives to system care; and the growing numbers of professionals within the system and

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[1] Mary Viventi, Kent County Community Mental Health Center, "Evaluation Correspondence" to Department of Mental Health and OUR Project, October 7, 1986.

state government who support funding for consumer-run programs simply because they meet real needs and have proved beneficial to participants.

To address some of the issues raised by an "exposure" strategy, another strategy to change practices of the mental health system is required: mandated accountability.

Changing Practices: An Accountability Strategy

In the practices of mental health "normal science," there are no requirements that practitioners be accountable for treatments they render for fees (unless they are sued by their clients for malpractice or otherwise subject to investigation for fraud).[1] This circumstance is determined by a number of ideological, economic and political forces operating in this society.

For mental health professionals, the political emphasis of most professional associations affords a kind of "social protection" through the mechanisms of professionals-only "peer reviews," extensive Congressional lobbying efforts to maintain physicians' fee-for-service payment practices,[d] and by close association with drug companies to whom they provide an endless stream of customers and from whom they receive support for their professional journals and associations (Breggin 1983, 256-259).

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[1] A discussion of this feature, and suggestions for achieving provider accountability through restructuring "Treatment as a Capitalistic Venture: A More Radical Solution," can be found in Magaro et al. (1978, 214-226).

Close association with, and support of, drug companies and continuing--or increasing--use of their products by professional associations show few signs of change. "Professional duty" to associations has been described as upholding such allegiance, notably by a past President of the American Psychological Association, which heretofore has been the least medically-treatment oriented of any mental health professional organization. In his article describing psychologists' professional duty, DeLeon (1988, 313) quotes a statement by Senator Inouye at an Hawaiian APA meeting, which he also supports:

> (M)embers of [mental health care related] professions have been successful ... in amending their state practice acts to allow them to independently utilize drugs where appropriate ... In my judgment, when you have obtained this statutory authority, you will really have made the big time. Then, you truly will be an autonomous profession and your clients will be well-served (Inouye in DeLeon 1988, 313).

DeLeon continues:

> In my judgment, there is no question that psychologists can, and should, accept this authority and responsibili ty. ... If psychologists are to be able to "diagnose and treat" independently, then we should not continue to accept any arbitrary limitation on our practice ... we should continually strive to ensure that the consumer of our services has ready access to the most current "state of the art" mental health care available (DeLeon 1988, 313-314).

DeLeon's robust support of achieving "the big time" through increasing prescriptions for psychotropic medications, and achieving prescription-rights parity with medical doctors[1] did not include note of any controversy surrounding the issue.

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[1] Medical doctors are revealingly described in the article as "another profession ... economically and emotionally competitive with ours" [i.e., clinical psychology] (DeLeon 1988, 313).

In this instance, it can be seen that the political clout of professional associations is another substantial force maintaining the status quo, and one indicating need for sophisticated strategies when system change is the goal.

The "social protection" afforded by professional associations is also perpetuated by administrative rules which do not consider accountability *to consumers* in evaluations of the work of their practitioners. Rather, an "evolution toward accountability" is suggested in terms of "reimbursement for psychological services ... directly tied to being able to demonstrate objectively that the particular services rendered were both cost effective and the "treatment of choice" (DeLeon 1988, 311). Beyond the questionable issue of "choice" for public mental health consumers whose economic situations preclude them from seeking mental health care outside the confines of treatment modalities in vogue and/or available in Community Mental Health Centers, the exclusion of treatment outcome for the involved consumer, as a facet of accountability, reveals the power of such associations. They have successfully "mobilized the issue [of accountability to consumers] off the political agenda."[6]

This circumstance is fueled by psychiatric ideology: explanations of "mental illness" which discount communications from "mentally ill" people who might otherwise be consulted as to treatment outcomes were the explanation challenged. Researchers receive funding for studies that will maintain the dominant explanations of the phenomena (e.g., genetic research in schizophrenia or manic-depression) they have been taught by their instructors and commonly receive rejections for non-mainstream research proposals. In their turn, teachers rely on current research to guide them in continued education of new generations of students. Thus, far removed from treatment settings, the system is (also) perpetuated by professionals with the least "officially recognized" power. Yet, their teaching may well affect the implemented definition of the situation used in treatment by practitioners they educate.

Even if practitioners wholly depart from the training they have received formally during actual practice (a finding Freidson [1986] noted), there is still no official means by which they can be held accountable for their actual service to clients. Moreover, there are many reasons and research studies they can cite which levy the blame on the consumer for unsuccessful treatment outcomes: differences in class background, verbal abilities, gender, race, or nationality can "explain" the failure of certain psychotherapies, as can non-compliance with drug regimes, premature client-initiated termination of therapy, or simply the "resistance" of the consumer. The therapist is exonerated by virtue of his or her professional position from being accountable for the outcome of treatment which they have conducted. Their professional skill, perseverance, or ingenuity in overcoming whatever difficulties or "resistance" presented by the consumer is not called into question. They receive fees or third party payment regardless of treatment outcome. They simply have no stake in outcomes, beyond whatever personal needs, philosophy, or morality that guide their professional behavior during treatment. These latter elements are important, and no doubt apply to the majority of practicing therapists, but bureaucratic assumptions that practitioners will strive to be ethical, efficacious, and successful in the psychotherapy situation are not sufficient to ensure that therapists will be accountable for treatment outcomes involving consumers, especially for those deemed "severely mentally ill."

Part of the lack of accountability built into professional mental health practice may be rooted in the stigmatized situation of the "mental patient" who society generally scapegoats and/or shuns. This ensures that practices of professionals will remain undisclosed--until consumers enter the public discourse.

For their part, consumers are generally deemed not accountable for the quality of participation in treatments because of their "mental illness" which allegedly impels any and all behaviors seen in treatment settings. There is no question that some consumers experience social vulnerability and its attendant accommodation forms (i.e., "symptoms") as a medium over which they have no control, but it is equally true that even during periods of psychosis people have respites during which they are not psychotic.

I contend that consumers need to be recognized as responsible for non-psychotic actions they choose to pursue. Psychoanalytic psychology might argue that "freely chosen" actions are a contradiction in terms for a severely disturbed person, but field research leads me to believe otherwise.

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I have observed several ABC consumers presented with an array of voluntary choices sequentially chose activities which result in forcing others to act on their behalf, usually enabling them to receive inpatient care. The most common route to this end appears as a pattern. An employee or full-time volunteer at ABC chooses to stay away from the organization during a workday for reasons other than physical illness (e.g., boredom, lack of interest, avoidance of ABC-related work problems). In several instances I have witnessed, persons involved make this choice knowing that the lack of structured activities involved in "days off" had previously contributed to an exacerbation of felt anxieties or fears. When the anxieties or fears escalate away from co-workers and/or supportive peers at ABC, the involved consumer's next choice is contact with Emergency Services (i.e., the emergency treatment component of the local Community Mental Health Center) rather than a return or contact with known supporters at ABC. At Emergency Services, consumers ask for assistance with the encountered coping difficulties. Rarely has the sequence of events leading to inpatient care stopped with contact at Emergency Services: in fact, in the five years I have been involved with ABC consumers, I have never known this to happen. At most, inpatient care has been delayed by immediate refusal to admit a consumer to the hospital, but this most often results in consumers' "acting out" behaviors that will ensure incarceration, such as harm to self, threats to others, and/or onset of uncontrollable fear or anxiety states that render the person virtually incapable of adequate self-care.

Thus, the first voluntary choice made, to stay away from ABC (paid or volunteer) work, begins the sequence of events that can lead to hospitalization. This first choice is the most voluntary of the subsequent choices consumers make. It is also the point at which consumers can be held most accountable for their own actions, since they are not yet disabled by anxiety or fear, although they may fear an encounter with disabling fear or anxiety if they do go in to work. Thus, becoming accountable for their own actions may involve some risk-taking on their part. Support for this risk-taking needs to be available from consumer communities <u>and</u> practitioners of the system.

<u>Policy Recommendations to Achieve System Change</u>

The question to be addressed in policy development is: given the institutional linkages that maintain the mental health system in its current form (i.e., economic, political, and ideological), how might accountability and exposure strategies be accommodated? Informed by knowledge of linkages between practice and policy discussed in preceding pages, it is clear that change in practices must be the first priority to eventual change in policy.

If mental health bureaucracy administrators and planners remain incapable of formalizing accountability mechanisms for practitioners they employ in the public sector, and whom they license for practice in the private sector, a beginning step might be made by practitioners and consumers who mutually establish areas of accountability for the duration of their shared psychotherapy experience.[1] A tentative beginning in this area is outlined below. Following a time-limited period of "trial and error," practitioners and consumers (and other advocates of change) involved may unite to lobby administrators of the system to mandate such a practice and incorporate the idea as a formal policy.

After consumers' selection of a practitioner with whom they believe they can accomplish personal goals important to them (e.g., reduction in anxiety or self-actualization as opposite end points on a wide continuum of goals they may recognize or value), the practitioner and consumer meet for a "discovery" interview. This meeting introduces consumer to practitioner, and allows details of previous treatment history to be discussed. It also allows the practitioner opportunity for self-disclosure about psychotherapy philosophy, personal philosophy or moral convictions that would affect how the practitioner conducts therapy, and any personal experience the practitioner may have had with resolving significant personal dilemmas that might convey empathy for the consumer's situation. The "discovery" interview would also focus on exigencies in the individual's social context, such as available family support and/or quality of relationships; source and level of income; job history; school history; leisure activi-

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[1] This idea is premised on my research finding that psychotherapy represented the most used and most appreciated of routine treatments in the system among participants (public and private) in this research sample.

ties. The practitioner should also be alert to other variables of social import likely to affect outcomes, and share these insights with the consumer. These variables include (but are not limited to): non-mainstream sexual preference and/or political orientations, race, gender, nationality, religious preference, etc.. Due to the complexities of issues involved, the "discovery" interview should be scheduled for a minimum of two hours.

Because there is risk-taking involved, the practitioner, as guide and example, can develop a statement as to areas of accountability that he or she agrees to in preparation for the next meeting with the consumer. These areas might include: provision of comprehensive information about any treatment regime suggested; an initial estimate of the intensity and duration of psychotherapy (e.g., two meetings a week for three years) likely to apply to the situation of the individual consumer, given the context provided in the "discovery" interview; and a concrete statement concerning objectives of the psychotherapy (e.g., eventual employment for the consumer; eventual attenuation of severe anxiety experienced; ability to experience comfort in social settings, etc.). The major point in this endeavor would be to make the most reasonable assessment of the psychotherapy situation given a comprehensive understanding of personal and social situations confronted by the consumer <u>and</u> the practitioner, and to impart these assessments to the involved consumer.

Following this example, the consumer can be asked to develop a statement that reflects areas of accountability they are willing and/or feel able to propose. Initially these may include: regular attendance at scheduled therapy sessions; regular attendance at their paid job or volunteer work site; development of a "coping map" that outlines steps to take/sources to contact when they feel their abilities to cope successfully are eroding, etc. It may also note situations to avoid when the latter process is occurring (e.g., drinking or drugging; withdrawing from social interaction when upset).

Both parties to these "accountability agreements" would respect the boundaries proposed by the other and negotiate periodic revisions as conditions allow or demand. The immediate benefit to promulgation of such agreements would be that both parties are substantially involved in defining the situation for the consumer and negotiating a working relationship toward a mutually articulated objective(s).

Actor-Focused Policy Change Suggestions

Other suggestions offered below, attempting to meld practice with policy changes in order to achieve actual change in both practices and guiding system policy, draw on insights revealed through data analyses, consumers' recommendations, and literature reviews. They are presented here in cursory form because several suggestions depend on future research endeavors, which I address in the next section of this chapter. I divide the topical areas for policy recommendation by the actors most affected by and/or integral to their accomplishment (i.e., consumers, practitioners, system administrators, professional teacher-researchers, local community activists, professional and other elites in society), although it is clear that there are substantial areas of over-lap between actors who will be involved in making such changes.

Policy suggestions: Consumers

-Allow consumers free choice of practitioners to facilitate selection of desired psychotherapy approach (e.g., psychoanalytic, short-term, behavior modification, crisis-oriented only).

-Structure paid employment opportunities for consumers in state and local hospitals, which subsequently allows greater opportunities for: a) peer to peer referrals to/publicity of local consumer-run programs or organizations; b) consumer monitoring of actual inpatient care practices; c) addressing stigma problems of expatients discriminated against (and demeaned) in other community work-settings.

Policy suggestions: Practitioners

-Structure salary and/or time-compensation incentives for practitioners' seniority (to achieve less staff turn-over).

-Provide increased salaries for practitioners and auxiliary personnel in all categories, including clerical and direct-care workers (also toward the end-goal of achieving less turn-over).

-Require a detailed rationale for practitioners' prescription of psychiatric drugs or electroconvulsive therapy (and any other documented brain-damaging treatment such as psychosurgery) including citation of research used to defend claim that it is needed and warranted; expected benefits of treatment prescription and time period within which benefit would be anticipated; and expected duration and intensity of treatment. The practitioners' supervisor would be mandated to review and approve treatment prescriptions offered; and the involved consumer(s) must sign the rationale and be provided with their own copy of it.

-Mandate hospital staff, including inpatient therapists, to develop a concrete description of what constitutes an "emergency" in treatment settings for which any one of the following would be employed: seclusion, forced take-downs, restraint, injections of psychiatric medications against consumers' voiced opposition.

Policy suggestions: Administrators

-Require consumer representatives on all relevant advisory boards for mental health treatment, programs, policy planning, and lobbying organizations. All consumer representatives would be recognized as voting members, in similar capacity to all other advisory board members.

-(Prior to abolishing involuntary medical treatments for non-organic, social coping difficulties), recognize the same civil rights for "mental patients" that medical patients have (i.e., non-contestable, [actual] right to refuse treatment without penalty; right to <u>informed</u> treatment; right to change primary provider without fear of exclusion from all other system services--i.e., "case closed"--if this option is chosen; right to receive and send uncensored mail, unmonitored phone calls, etc.).

-Comply with regulations governing Community Mental Health Centers (CMHCs) as mandated in the 1963 Mental Health Act establishing the network. Specifically, adhere to requirements that CMHCs' Board of Directors be comprised of genuinely representative community members (including consumers), as revealed by demographics of the catchment area. (This represents a first step toward eventual decentralization of the mental health care bureaucracy.)

-Develop salaried position(s) [and/or a work-study internship agreement with local university or community college] for community-based researchers to procure paid employment for recovering and/or recovered expatients the system included in pre-vocational and vocational programs. Researchers should be alert to successful programs (e.g., Fairweather Lodges,[f] consumer-run businesses) already operating in the community, state and nation. Volunteer employment possibilities, amenable to consumers' needs for meaningful, worthwhile and helpful activities, should be identified and procured for consumers not yet able to assume competitive employment (e.g., positions in retirement centers and nursing homes).

-Inaugurate use of the applied "theory of empathy" (in Robb, 1988) in outpatient and inpatient settings, and require practitioners to engage in two courses of study in its application as a contingency of continued system employment. (These possibilities can be explored with practitioners and administrators at the McLean Hospital in Boston, where it is already in place and outcome evaluations contrasting this approach with traditional approaches are available.)

Policy suggestions: Professional-Elites

-Argued on the grounds of cost-benefit appraisals, lobby for and/or support or draft legislation for the purpose of increasing allocations to consumer-run alternative programs.

-Decision-makers at the National Institute of Mental Health need to expand criteria according to which research proposals in the area of mental health are given funding. As outcomes of treatment, practiced according to standards of care recognized by insurance companies and courts of law are shown to be ineffectual for consumers, these new data can be used to defend the need to fund innovative mental health research proposals.

-Elites without mental health system affiliation (e.g., Congressional representatives; private foundation administrators; philanthropists; locally recognized civic leaders, etc.) should assist in drafting legislation or policy requiring professionals (practitioners, administrators, teacher-researchers, professional elites) to reveal the data base upon which standards of care for major psychiatric drug prescriptions, electroconvulsive therapy (ECT), and psychosurgery in the mental health field are founded. Once revealed, the data base should be expanded to include critical studies concerning these procedures. When a comprehensive data base is developed, funding to allow cross-study comparisons, replications, and verification of found effects should be implemented. Standards of care which promote known brain-damaging treatments must be reversed until or unless the scientific community verifies that brain-disabling treatments are of greater benefit than all other non-invasive treatments available.

Policy suggestions: Teacher-Researchers

-Expand interdisciplinary approach to formal education of prospective counselors and therapists, mandating inclusion of courses of study in: *nutrition* (as many physical conditions caused by vitamin deficiencies mimic what are routinely labeled "psychiatric disturbances")[9]; *sociology*, including special attention to *feminist and stratification scholarship* (to alert practitioners to social variables affecting onset of coping difficulties, ways in which society institutionalizes certain social vulnerability states [race, class, gender], interrelationships between economic, political, and ideological forces which maintain typifications of certain cohorts of people such as "mental patients," black people, poor people, women, etc.); *critical theory* (as a way to stimulate self- and professionally-reflexive thought about practices in the field); and *qualitative research* strategies (towards ascertaining what has been lost by ignoring, distorting, or discrediting consumer-focused in quantitative research studies dominating the mental health field).

-Encourage innovative approach to research in the field (which can easily be posed in terms of need for new, effective approaches to social coping difficulties).

Policy suggestions: Community Activists

-Identify sources of support for changing practices in mental health care. Encourage supporters to become involved in coalition for lobbying efforts to achieve the following objectives:

-Make on-going funding for CMHCs contingent on success of treatment outcomes and/or documented efforts toward changing the "usual and customary" modalities of treatment and on authentic inclusion of consumers in the workings of the CMHC (on advisory boards, as employees of the hospitals, etc.).

-Demand more money for consumer-run programs from local and state legislators. This will need to be in tandem with efforts toward restructuring national spending priorities (e.g., deflecting money from military defense expenditures toward social provisions for all citizens, including nationalized health care, improving air and water quality, enhancing community-strengthening business ventures and more).

-Develop incentives for private families to house consumers in need of housing (tax credits, cash payments), whose success, in terms of assisting the consumer and providing membership in a family/"community," has been documented in the village of Geel, Belgium.[h]

-Undertake efforts to lobby against increasing the numbers of people with medical prescription rights (i.e., clinical psychologists).

-Publicize actualities of contemporary practices in mental health care and the documented ineffectiveness and damage caused by same. Document and publicize the benefits of non-invasive treatments (e.g., longer-term psychotherapies) and innovative programs developed and operated by consumers.

-Explore the political efforts (e.g., coalition building) that resulted in the outlaw of mental institutions in Italy.[1] Document and publicize the effects of this move, and the rationale used to justify it.

-Demand a public accounting of the increased death rate for people incarcerated in state institutions, with special attention to conditions that promote and allow fatal accidents and suicides.

-Establish a nation-wide data base which documents physicians and other practitioners who have been successfully sued for malpractice in mental health care. Employ this data base in screening practitioner applicants for positions at Community Mental Health Centers and state hospitals (as a way of addressing the current practice of allowing doctors convicted of malpractice for sexual abuse, over-drugging, etc., to simply relocate in another part of the state or country). In connection with this, lobby to require that ALL employer references offered by practitioner applicants be contacted to ensure that the reason stated for leaving a previous position is accurate (this protects consumers from practitioners who were asked to leave for "unethical or untoward" treatment practices, but not successfully sued or formally charged, from unwittingly becoming their next victim(s)).

-Insure that quality, low-cost housing is available and/or developed for persons in need in the community. As possible, explore possibilities of renovating older buildings in need of repair for communal living situations desired by community residents. (These efforts are toward the goal of achieving shelter for all persons in need, whether they are consumers or not, since living on the streets has been documented [see Hombs and Synder, 1982] as rendering individuals socially, physically, economically, and politically vulnerable.)

These suggestions are not exhaustive, nor do they recommend changes easily achieved. To speak of the need to "enhance communities" or "decentralize" the Community Mental Health Center network and the National Institute of Mental Health is not to deny the mind-boggling problems acting on such suggestions indicate. Nor do I intend to suggest that such changes will be realized in our life-times. I do contend, however, that these efforts <u>must</u> be undertaken. And we must begin where we can, in our own communities, in our own families, with our own friends and neighbors. We have much to lose if the mental health system is allowed, by our inaction, to proceed with "business as usual." It is time to listen, time to learn, before the failures in care and treatment pass on to another generation.

It may also be apparent that substantial discussion and attention to any <u>one</u> of the issues raised by the preceding policy/practice change suggestions will be required to achieve the objectives outlined. Such detailed attention to issues of policy lies beyond the scope of this dissertation. Nonetheless, it is hoped that these recommendations provide initial direction in efforts to change the structure and practices of the contemporary mental health care system.

Some of the concerns raised by these suggestions comprise areas for fruitful future research, examined in the next section.

Areas for Future Research

In consideration of concerns raised by policy and practice change suggestions, there is a wealth of additional research needed in the mental health care area. The immediate and profound need is for research which includes consumers' voices; reports their actual experiences in the care system; acknowledges and enhances, through cogent analysis, the contribution consumers make to critiques of the care system; and offers opportunities to explore a myriad of variables which affect the development of individual and social coping difficulties. Research with consumers is long past due. Many problems in the field of mental health research, practice, and policy emanate from research studies which eschew consultation with the very people such research is said to "benefit."

A great deal of needed research concerns replication of previous research studies whose results have been refuted or opened great areas of controversy about specific treatment modalities. Unfortunately, one significant obstacle to conducting replication studies is structurally encouraged by institutions of higher learning. By and large, graduate students, representing an immediate pool of people required to do research, are discouraged (if not prohibited) from replicating previous studies, especially at the doctoral degree level, where original research is mandated. While this is arguably important for their development as researchers, it also depletes the numbers of people available to do replication studies. Fortunately, research for masters-level degrees is less bound to "original-only" strictures and may represent a more amenable atmosphere for conducting replication studies and/or secondary analyses studies (the latter of which may be equally important in mental health research endeavors).

In addition to need for replication studies, there is clear need for community studies that focus on a variety of variables affecting consumers' living and working situations (e.g., volunteer or paid work sites; housing development possibilities; consumer-group employment possibilities after venture capital is secured, etc.). Also important are community studies which connect macro-level forces with micro- or local-level situations affecting consumers in particular and other low-income people in general (e.g., social impact assessments of proposed legislation to reinstate narrow definitions of "dangerousness" used as the vehicle to achieve commitment to psychiatric hospitals).

More specific to the issues raised by the emergent "theory of social vulnerability states" is research which augments the findings of this study. What additional qualitative research is needed to broaden the base in which this theory is grounded? How might the reciprocally reinforcing effects of various situations of social vulnerability, posited by this theory, be quantified? How might quantitative documentation of the benefits of participation and embrace of a community be achieved? While I have argued for needed qualitative research, particularly when conducting research with mental health consumers, I also recognize the value of quantitative studies which may enhance the findings of a small study such as this.

For example, one approach to study the effectiveness of mental health consumer-run programs is to evaluate their capacity to help expatients reintegrate to community life and activities following hospitalization and avoid the need for readmission to the hospital. (This is a formal objective of the ABC organization, and the rationale upon which funding allocation was approved.) This study can be modeled on procedures associated with cost-benefit evaluations (see e.g., Rossi and Freeman 1982).

Within the last ten years, theoretical perspectives in studies on stress, stress states, social support, and social support networks (Holmes-Rahe [1967]; Hammer [1981]; Belle [1982]; Wethington and Kessler [1986]; Jacobson [1986]; Dohrenwend and Dohrenwend [1978]; McFarlane et al. [1980]; Walker, McBride, and Vachon [1975], among others) have been richly developed. These research findings provide the framework for suggesting hypothetical constructs (outlined below) which might be used in evaluating programs such as ABC's "Help

Project" (which is specifically focused on aid to the recently hospitalized individual and/or people in extreme states of social vulnerability requiring advocacy assistance to procure basic needs). The following are examples of such hypotheses:

> _Causal hypothesis:_ Psychiatric rehospitalization results from an absent or poorly developed social support network in the community to which mental health consumers return.
>
> _Intervention hypothesis:_ Providing a social support network (i.e., an accessible consumer community) for people recently hospitalized will reduce the need to rehospitalize.
>
> _Action hypothesis:_ Increasing access to social support network [24-hour, 7-day week availability of contact people and support services through the ABC's Help Project] prevents rehospitalization.

Impact can be defined in terms of the causal hypothesis and the intervention hypothesis, with attendant measures for success of each. Measurement of the intervention hypothesis might use an existing instrument, such as a previously validated Social Relationship Scale (SRS) (McFarlane, et al. 1980). The scale measures an individual's support network in terms of four dimensions: _structural_ (size, density, frequency of interaction); _interactive_ (reciprocity, symmetry, directionality, content area); _qualitative_ (linkage, friendly-hostile dimensions); and _functional_ (instrumental and/or expressive).

> _Causal hypothesis:_ Absent or poorly developed social support networks (i.e., lack of connection to a supportive community) lead to an increase in number of rehospitalization days for former mental hospital patients.
>
> _Measurement of Causal hypothesis:_ Determine hospitalization patterns for participants in study during preceding 2 year period. Quantify rehospitalization data for each Help

Project consumer during study period. Obtain initial measurement of SRS at beginning of study.

Intervention hypothesis: Presence of an adequately developed social support network/community will reduce the need for rehospitalization among Help Project consumers.

Measurement of Intervention hypothesis: Assess statistical significance between initial measures of hospitalization patterns and rehospitalization data for study period and initial measures of SRS with end measures of SRS at conclusion of study period.

Control groups among Community Mental Health Center consumers not participating in ABC and/or documentary construction of control groups of CMHC participants (through search of case records for consumers who can be matched on relevant variables) can provide the comparison basis for the cost-benefit appraisal.

It is anticipated that a cost-benefit evaluation would reveal that a significant number of people have remained in the community who would otherwise have returned for hospitalization; and that the cost differential between funding for programs such as the ABC Help Project ($25,000/year for services to 800 consumers) versus costs of incarceration per person served (over $20,000/year/person in state hospital care) is considerable.

To posit that the effects of social support are unilaterally positive in this evaluation design coincidentally allows qualitative assessment of the actual effects of social support. For instance, Deborah Belle's important (1982) study asserted that:

> For the low-income mothers who were interviewed for this study, social ties proved to be a two-edged sword, associated with important forms of assistance and social support and yet also associated with troubling worries, upset, and concern (Belle 1982, 142).

In light of these findings, it would be important to assess evaluation study data to ascertain the qualitative effects of social networks:

> In determining risk [or benefit] one must ... ask whether the social network provides emotional and instrumental support, or whether social ties actually create more burdens than they lift (Belle 1982, 241).

A significant contribution to social support research might be made if features of interaction involved with the latter versus the former aspect of social support can be determined.

Such studies can be a useful foundation from which lobbying efforts to increase funding of consumer-run programs on a cost-benefit basis on local and state levels can be argued. It also provides data which may be employed to publicize the benefits of consumer-run programs on local, state, and interstate levels, especially if Departments of Mental Health in other states have participated in the projects (e.g., as a funding conduit) and are willing to assist in disseminating information.

Importantly, cost-benefit appraisals can be easily replicated and used in other parts of the state and nation where consumer-run programs are in operation. This facilitates additional research and stimulates new questions and strategies for study. Are benefits to consumers participating in consumer-run programs realized in Michigan similar to those in other regions? Are beneficial results affected by local or state unemployment levels (precluding employment opportunities for consumers) or degree of industrialization in the state (i.e., are diminishing manufacturing jobs the dominant source of employment)? Are there cottage industries that could employ consumers, or be developed by them? Do benefits differ by rural or urban settings? Questions such as these may serve as a spring board for more quantitative _and_ qualitative studies.

Another area for additional qualitative studies, guided by strategies and design similar to those incorporated in this research project, is readily available in Michigan. There are several ABC drop-in "satellites" now in operation as a result of endeavors through the ABC OUR Project. To address questions concerning the effects of charismatic leadership attributed to Ashton (i.e., is it an essential element in successful consumer-run organizations? Is the positive effect of charismatic leadership grounded in duration or intensity of exposure to it?), groups initially organized through his efforts, but who operate largely on their own, provide one comparative data base for findings from this Lansing-based study.

Also accessible in Michigan are several consumer-involved (but not consumer-run) programs likewise funded by the Michigan Department of Mental Health as consumer-initiated "alternative services," which depart in various degrees from the ideal of solely consumer-operated programs. The dimensions in which these differences are realized, particularly with respect to benefits of participation reported by the involved consumers, may reveal important facilitators and obstacles to achieving fully consumer-run programs. Questions which might be important in these areas include: Was the idea for the program developed by professionals or consumers or mutually negotiated? What operating procedures are in place and who developed them? What crisis situations have these groups confronted; how were they resolved; and what actors were dominant in their resolution (professionals or consumers or both)?

Research studies focused on these kinds of questions will assume increasing importance as funding for consumer-initiated alternative projects continues at current levels. They may be particularly important if funding levels fall, and all social program advocates vie for dwindling resources available (unfortunately, this appears to be the more likely scenario, as the Bush administration upholds the New Federalist policies of the Reagan years).

Finally, it is absolutely essential that researchers work together to develop alternatives to an understanding of personal or social distress without reliance on medical models of "illness" or "treatment" for non-organic conditions. This is not synonymous with abandoning all recourse to hospitalization nor psychiatric medications which may be of benefit in severely time-restricted, crisis situations. When alternatives to this source of emergency help are not consistently available--or not yet developed--it is simply inhumane to suggest to people in extreme states of social vulnerability that because available help is inadequate, it should be abolished or shunned altogether. Nor is it realistic to imagine that members of consumer organizations such as ABC, family, or friends will always be competent to address the complexities of problem-solving with or for people in emotional turmoil or severe crisis.

The profession of mental health care developed for many reasons, but it was in part impelled by the angst of families and community citizens no longer able to help involved persons resolve their experience of extreme social vulnerability. The "expert help" sought by distressed individuals or those involved in their behalf may be less "expert" than popularly believed, and also of less "help." But the experience of practitioners should neither be eschewed by researchers endeavoring to develop alternative understandings of the phenomena labeled "mental illness." Lest critical researchers distort their voices in the same way that acritical researchers distort or silence the voices of consumers, professionals in the field must also be included in reflexive discourse.

For these reasons, future critical research endeavors in the field of mental health will be best served through joint and/or complementary research ventures informed by an interdisciplinary approach. They must be attentive to the consumer perspective, and alert to the ever-present dangers of medical bias and unwitting incorporation of dominant social ideologies in research methods and methodology and/or in subsequent theory development. Consumers' experiences at Alternatives By Consumers highlight the importance of connection to a supportive community when freedom from past shackles is an objective. Researchers seeking this objective in mental health studies can--and must--learn from their example. *It is only through cooperative research that our understanding of the human condition will truly be advanced.*

Contributions of Study

During the 1980s, civic leaders, expatients, their friends and family members, professional or lay advocates, and mental health professionals have expressed a growing interest in consumer-run mental health care programs. To date, this interest has taken the form of state funding for groups such as Alternatives By Consumers. In large part, the impetus to fund consumer-initiated projects emanates from an acknowledgement that alternatives to traditional mental health care are a significant, if not desperate, need in this society.

Estimates of people deemed to be "severely" or "chronically mentally ill" in the United States exceed 2.4 million. Deinstitutionalization practices return hundreds of thousands of expatients to local communities, where their consequent homelessness, poverty, ill-health and vehement, if not violent, ostracism in community settings is rendered visible--and problematic. Inclusion in the formal system of mental health care has not restored their mental health, nor appreciably altered their much-publicized, degraded living situations. The reality of that system, and how it affects the lives of people using it, must be shared with professionals--and concerned others--who rely on formal mental health treatments and standards of care to ensure that adequate help is offered to those in great need. Without accurate information, the system--and reliance on it--will continue to operate in "usual and customary" ways.

My primary intent in this research project has been to give voice to mental health consumers, long denied access to discourse concerning mental health, mental "illness," and related treatments. I have given voice to the critiques that are being offered by consumers in the mental health system <u>of</u> that system. Some of these critiques of current program offerings were articulated in the interviews; others became apparent by analyzing the types of advocacy activities undertaken by this consumer organization; still others were revealed in the history of ABC and the struggles--and victories--it has had in the community.

Research findings have illuminated important differences between explicit mental health policy and actual mental health care practices, revealing a tacit mental health policy in operation. Project results have also affirmed previous sociological studies that depict significant, qualitative differences in medical and mental health care provided to low-income or public consumers versus private sector, higher income consumers.

Importantly, this research has provided me with opportunity to compile extensive primary data which refutes assumptions made about mental health consumers and the efficacy of treatments prescribed to benefit them. Rather than encountering incapable, confused individuals, with little grasp of the workings of the mental health system or society, I found people whose commentary on system and social dynamics were sophisticated and insightful. Their perseverance in struggling to overcome past tragedies of circumstance or human design is courageous, and often inspirational. Despite discontinuity of care, subject to brain-damaging and ineffectual treatments and/or programs allegedly designed to restore them to reasonable vocational and social futures, they survive. Against all odds, they grow and change and reach out to their peers at ABC, nudging others towards mental health as well. I am privileged to have been a part of their community.

Attention to the consumer perspective on early family or caretaking situations; the actual experiences of treatment; advantages and disadvantages of these treatments; articulation of their beliefs about "mental illness" and specific diagnoses; and their feelings about the ABC organization-community has allowed the emergence of the grounded theory of mental health consumerism. Conceptually elevated to a tentative "theory of vulnerability states," the grounded theory reveals that two essential components needed to comprehend the mental health consumer experience are also useful in articulating components common to disadvantaged social position among other sub-populations in the society.

The first component, social vulnerability, acknowledges that people who are at social disadvantage are more vulnerable than others not at social disadvantage. This social vulnerability evokes a need for, and susceptibility to embrace, a definition of situation/self that resolves the experience of extreme social vulnerability. The second component, participation in a supportive community, acknowledges that investment of time and energies in an environment providing an altered definition of situation/self heightens the likelihood that new definitions will be embraced _and also_ that social disadvantages can be assuaged by "emotionally corrective," supportive, and reciprocal social interactions, coalescing in the experience of belonging.

When the experiences of disadvantaged persons are seen through this theoretical lens, a shared human attribute is unearthed. All human beings are vulnerable at birth; most persons are provided with supportive environments that enable this early social vulnerability to be resolved. When early environments are not supportive, whose complexities may include noxious interpersonal dynamics; physical disabilities or health problems; impoverished living situations; restricted access to educational opportunities; and/or a generalized social disregard for persons in specific social categories of gender, class, or race, the possibilities of resolving early social vulnerability recedes. As more and more experiences contribute to the sense of social vulnerability (e.g., gender, race or class discrimination), persons may come to occupy "social vulnerability states."

The accommodations that mental health consumers make to their "social vulnerability states" assume characteristic forms usually subsumed by definitions of functional "mental illness" or codified disorders under this rubric (e.g., "manic-depression"). Similarly, accommodations other socially disadvantaged persons make to their "social vulnerability states" have also been characterized in codified ways (e.g., Oscar Lewis' [1966] theory of "The culture of poverty;" Sennet and Cobb's [1972] theory of the "Hidden injuries of class"). In this conceptualization, there is no inherent need to medicalize characteristic accommodations of people experiencing "functional" and/or non-organic "mental disorders" (i.e., what I have consistently referred to as coping difficulties) in order to understand their meaning or their import.

These aspects of the "theory of social vulnerability states" can contribute to the development of powerful, new theories that do not depend on codification nor distortion of research subjects' experiences for comprehension. In addition, the embrace of our human <u>commonalities</u>, allowed by the synthesis of a wide variety of social actors' viewpoints in cogent theory, may stimulate further attention to social processes which unify, rather than divide, the populace. Achieved through application of a critical and interdisciplinary perspective, grounded in authentic human experience, the "theory of social vulnerability states" illuminates the need for community we all share, scholars and non-scholars, consumers and non-consumers alike. It is hoped that this theoretical contribution may impel greater movement toward that end.

CHAPTER END NOTES

(a)One recent example of this dynamic was brought to life on the August 17, 1987 Oprah Winfrey Show (#W241), when mental health consumer advocates, the President-elect of the American Psychiatric Association (APA), Dr. Fink, and a critical researcher/ practicing psychiatrist, Dr. Peter Breggin (1983) discussed drug company funding of the APA and drug research; and the value of psychiatric drug treatments for people labeled "mentally ill." Two excerpts from transcripts of the show illustrate the psychiatric establishment view (via Dr. Fink's comments) of drug critiques as impugning integrity of practitioners and as a radical, atheoretical(/unfounded) attack on the evaluation of such drugs by system personnel researchers (ironically members of the APA task force on the subject).

Judi Chamberlin (1978), an expatient advocate, asks Dr. Fink: "How can you have a scientific debate as to whether drugs are good or bad if the drug companies are underwriting the discussion? It skews everything."

Dr. Fink: "The assumption is that we're unconscionable ... that 33,000 psychiatrists are just a bunch of rats..."

Later, Dr. Breggin raises the issue of drug use and tardive dyskinesia. Dr. Breggin: ... If individual people want to take drugs, that's their privilege, but they should know that long-term therapy in 50% of the cases is producing [tardive dyskinesia] ..."

Dr. Fink: "Fifty percent of the cases--an outrageous overstatement. It's absolutely an outrageous overstatement."

Dr. Breggin: "The Psychiatric Association's [APA] task force on tardive dyskinesia said that--"

Dr. Fink: "Never said, never said 50% got tardive dyskinesia, never."

Following a commercial break, Breggin read from the APA task force report, which stated ... "Ten to 20% of the shorter-term, 40% and more of the long-term" [patients on these drugs develop tardive dyskinesia] (transcripts #W241, August 17, 1987, pp. 11-12).

These exchanges well illustrate the "regard" with which critical researchers in the field are viewed by the establishment.

(b)Interestingly, one personnel supervisor at a Community Mental Health agency used this line of reasoning to defend the practice of electroconvulsive "therapy" (ECT) versus a psychoanalytic psychotherapy approach during an "in-service training" session for Alternatives By Consumers' staff persons (which I attended) on ECT held at a local hospital (October, 1986). The consumer in question had received ECT for over 10 years, on a recurring basis (e.g., 3-4 series a year). When asked if any other approach, including psychoanalytic psychotherapy, had been attempted, the supervisor responded that the consumer needed "help" as quickly as possible and that such therapy took too long.(!) The irony of defending ECT use when such "treatment" had proved ineffective for recovery (not to mention brain-damaging) year in and year out for over 10 years apparently escaped the supervisor's notice.

(c)For inpatients of all ages combined, the rank and cause of death in Michigan state facilities were identified as: 1. Diseases of the heart; 2. Malignant neoplasms; 3. Accidents; 4. Pneumonia and influenza; 5. Suicide. For inpatients between the ages of 15-34, the rank and cause of death were identified as: 1. Suicide; 2. Accidents; 3. Cerebrovascular; 4.5 Pneumonia and influenza; 4.5 Chronic obstructive pulmonary diseases (Rates reported per 100,000 patient years). In Michigan Department of Mental Health, "Preliminary Report of Psychiatric Patient Mortality Rates," Prepared by Genice L. Rhodes, Director of Research and Evaluation Division, November 3, 1982, p. 8 (internal publication).

(d)"The greatest opposition to subsidy by the federal government of the initial costs of staffing community mental health centers came from the American Medical Association [AMA]. ... The AMA, representing primarily the interests of physicians in solo, fee-for-service practice, had a long history of opposition to any other form of practice or payment. ... Only in 1949, when it became clear that legislation supporting some form of compulsory medical insurance might be enacted, did the AMA go on record as favoring voluntary medical insurance programs (Bloom 1984, 22-23).

(e)This feature of organizational power, ability to mobilize issues off the political agenda, is informed by the work of Steven Lukes (1980, 24-25ff).

(f)Although I am aware, through employment and exposure at Alternatives By Consumers, that there are substantial problems with some of the "Fairweather Lodges" developed, many Lodges have proven to be successful and empowering for consumers involved. The idea is premised on organizing a small cadre of consumers before or shortly following their return to a local community as Fairweather Lodge members who live in communal fashion in a single-family sized house, are monitored by professional and non-resident workers, and are provided with initial funding to begin a consumer-run business (e.g., lawn care companies, janitorial services). The Lodges derive their name from George Fairweather, who developed the idea while teaching at Michigan State

University. For a report on the results of the first 25 years of Lodge operations in the U.S. (albeit largely acritical), see Fairweather (Number 7, 1980).

(g)There are many excellent studies of vitamin deficiencies as they relate to conditions labeled "mental illness" by others. For a cursory look at these connections see Mindell (1979, 246-48).

(h)A discussion of the Geel community, whose residents have provided home-based care to previously institutionalized persons since the 13th century, can be found in Bloom (1984, 14-15).

(i)For details on the Italian experience with deinstitutionalization and the abolishment of mental institutions, see e.g., Mosher (1983); Bachrach, et al. (1983); and Crepet and Deplato (1983).

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APPENDICES

A. Interview Guide

B. Recruitment Tape Transcription

C. Consent Form

APPENDIX A

Interview Guide

Note: For the reader's convenience, most of the probes used to gain additional information for specific questions have been omitted in this guide.

I. BACKGROUND INFORMATION

1. How big is your family and who is in it?
2. Where are you in the family birth order?
3. Are all these family members still living?
4. Who did you live with when you were growing up?
5. Where did you live when you were growing up?
6. What did your father [male caretaker] do for a living?
7. Did your mother [female caretaker] work outside the home?
8. How far did your parents [primary caretakers] get in school?
9. How old are you?
10. How many years of school did you complete?
11. Are you in school now? IF YES: Where? What are you studying? Do you like it? How far do you plan to go in school? IF NO: When did you stop? What made you leave? Would you like to go back to school if you could? What would you study?
12. Were you ever in military service? IF YES: How long? Where were you stationed? Did you get a regular discharge when you left?
13. Did you ever take any college courses? (Details)
14. Did you ever attend a technical or trade school?
15. Were you ever in a vocational rehabilitation program? IF YES: Are you still in it? What program? If no longer using: why did you leave/quit?
16. What is your marital status?
17. How would you define yourself in racial or ethnic terms?

II. CURRENT MENTAL HEALTH CARE INFORMATION

18. Are you currently in therapy? Is it individual or group? How often do you go to therapy?
19. How long have you worked with this therapist?
20. Can you describe your therapist to me? (i.e., man or woman; American, Hispanic or International; age; etc.)
21. Do you feel supported by this person? (Is s/he on your side?)
22. Can you call your therapist at any time and reach him/her? How does that make you feel?
23. What's the longest time you've ever worked with the same person in therapy?
24. How many therapists have you had in your life?
25. Do you believe there is such a thing as "mental illness?" (If yes) Can you give me your definition for "mental illness" ?
26. Do you know what your diagnosis is now? What is it? Have you had different diagnoses in the past? What were they?
27. What does this (current diagnosis) mean to you? Can you describe what traits you think go along with it?
28. Can you describe either the most disturbing traits or symptoms you experience OR the symptoms that have lasted the longest for you? Do you think these will ever go away?
29. Were you ever told what your prognosis--or the eventual outcome of your problems--would be? Do you agree with this? How does it make you feel?
30. Do you think there are factors that affect how certain people--including yourself--are treated in the mental health care system? (e.g., gender, racial or ethnic, sexual preference, body weight, intelligence level)
31. Are you on any psych meds? Did you ever take them? What kinds, how much? How do you/did you feel about taking them? (Do they help you?)
32. Were you ever told you would always need to be on medications? AND/OR Were you told you would always have problems of some kind if you didn't? IF YES: Do you think that's true?
33. Are you in any community mental health programs (other than therapy, if applicable)? (Example: Day Treatment or supervised housing)
34. Are you in any kind of other program or group--in or outside of the mental health system-- that is helping you recover and/or cope with your emotional problems?
35. Do you have a job? AND/OR Are you in any kind of job-readiness program?

36. Are you receiving any benefits? Did you ever? If yes, what kind? When did you start receiving this/these benefits? How long do you think they'll continue? (How long did they last?) Have you applied for any that were denied? (Why?) Have you lost any you once had? (Why?)
37. What is your housing situation? (e.g., independent --live alone or with family or with roommate(s); foster care home; group home; supervised housing or Night Care; temporary shelter or looking while staying with friends)
38. What were your previous 2 housing situations?
39. Do you have a job? IF YES: What is it? How long have you had it? Do you like it? Do you want to stay there? IF NO: what else would you like to be doing if you could? When was the last time you had one, if ever? How did you come to lose it? Do you think you'll ever work in a competitive job? Why or why not?
40. Are you looking for a job? IF YES: What do you hope to find?
41. What do you see yourself doing in 5 years?
42. How would you describe your physical and dental health? Do you see a physician routinely or only as needed? Is this true for the dentist, too? How do you sleep? Do you have trouble falling or staying asleep? If you remember your dreams, are there patterns or recurring themes in them? Do you have nightmares? Would you say you have eating problems? Do you ever have trouble eating--or not eating? Do you use street drugs, or alcohol? Would you say this/these are a problem area for you (feel out of control)?
43. Can you give me some examples of social activities you participate in? (Things you like to do with friends) How often do you do this/these?
44. What about other kinds of leisure activities that you do alone--hobbies and crafts? (Or something like reading, watching TV, creative writing, painting, etc.)
45. Now I want to ask you some questions about what are sometimes called "social networks"--

a) How many close friends do you have? (People who you can talk to about personal thoughts, problems...or who you can ask for help if you need it from them...) [No names, but # of]
b) About how often have you called each of these people in the last week? Last month? Is this typical?
c) How many home visits to/from these people in past week, month? Typical?
d) Have you shared the issues or concerns you've wanted to with these friends in the last month? Why or why not? Is this a typical pattern for you?

e) Where did you meet the people you have mentioned? (e.g., work--school--hospital-- ABC , etc.)
f) How many other friends do you have?
g) What kinds of things do you do with them?
h) About how often have you called each of them in the past week? Past month? Is this typical?
i) How many home visits to/from these people in the past week, month? Typical?
j) Where did you meet these people?
k) What about family members? Who, if anyone, in your family do you see socially--how often and why?
l) Is anyone in your family a person you could call if you needed help? Different if you needed money? Advice?
m) Why do you get in touch with your family members when or if you do?
n) Is there a one or two sentence description you could give me for your mother? Your father? Your brothers or sisters?
o) Did you experience physical or sexual abuse in the home you grew up in?
p) Who do you think of first--or call first--when you need help? Do you go to this person(s) for ALL kinds of help, or just certain kinds? What kinds of help? What kinds of help will you never ask them for? Who, if anyone, do you go to when you need that kind of help?
q) What about church or temple? Do you go? (How often?) Do you have friends there that are included in the people you've told me about? On a scale of 1--10, (10 being high), how important are your church or temple friends to you?

46. What do you think you give to your friends? (Why do you think they are your friends?)

III. PAST EXPERIENCES IN THE MENTAL HEALTH SYSTEM

47. Have you been hospitalized in a psychiatric ward or hospital?
a) How many hospitalizations for psych problems have you had? (Estimates are fine) Do you know how long you were hospitalized, all tolled OR what was the longest time you were in?
b) Have you ever been committed to a hospital involuntarily? Have you ever gone in "voluntarily," but under threat of legal commitment?
c) Were you ever refused admission when you wanted to go in?
48. Can you tell me what the causes or events were that lead to your last hospitalization? What about the first one?

49. I'd like to know some details about your hospital experiences. Has any of these happened to you, or are any of them things that you saw while hospitalized?

harm to self (Why do you think it happened? Inadequate staffing or physical deficits involved?)
theft of belongings
rape and/or physical abuse, beatings
availability and/or use of street drugs while hospitalized (How do you think they got in the hospital? Staff? Visitors?)
weapons (guns or knives)
medications, prescribed (Complaints about meds? People over-medicated? % of people on R's unit that were on meds?)
shock treatments
visitor(s) data
church attendance and/or availability of its equivalent
civil rights information (received or provided?)
boredom
escape(s) or walk-aways from hospital
phone call privileges
seclusion
"discharge syndrome" (did they experience and/or were they warned about its likely occurrence)
characteristics of hospital staff--if possible, broad over-view AND/OR If there were staff that were helpful to you, can you describe why or what they were like?

50. Please describe some of the hospital programs you've been involved with.
a) Can you tell me the strengths of these programs? What about their weaknesses ?
b) What about after-care or other out-patient programs you've been in? What were they? What were some good points about them? Some bad points?
51. Have you ever experienced foster care, guardianship, shelter placements, and/or jail ? (Describe) IF YES: Did this/these experiences have any long-term effect on you? What kind of effect?
52. Have you ever been in both public or private hospitals? What about therapy, private and public? What differences do you see, if any?

IV. EXPERIENCES WITH ABC

53. How did you first hear about ABC ? What was your first contact with it?
54. Why do you think you connected with ABC in the first place?
55. Has your life been affected by being involved with ABC? How?

56. What do you do here? (Staff, volunteer, patron of Help Project or Drop-in)
57. Have you ever ended contact with ABC (or stopped coming in for a while)? IF YES: Why did you reconnect? IF NO: What has kept you interested in it?
58. Can you describe the quality--or feel-- of some of the relationships you've established with staff, volunteers or patrons at ABC ?
59. Do you think some people get special attention, privileges or favors over others at ABC ? Can you describe the people who seem to be favored over others? Why do you think this happens?
60. Is it stressful working [or coming in or volunteering] here? IF YES: Why do you think so and/or what makes it stressful? How do you cope with the stress? Is there anything that happens here that affects the stress you feel? (If some days are better or worse than others, what makes the difference?) Can you think of anything that would change the stress you feel here?
61. Critical appraisal of the organization:

What do you think about the services that ABC provides to people? Do you think its programs meet real needs of consumers? (If yes, what needs; if no, why not or what else should it be doing--new program ideas)

What would you say is (are) the best thing(s) about ABC? What is (are) the most negative thing(s)?

Do you have a feeling that ABC affects this community? [If you don't think it affects the community, do you think it has affected how the mental health system is run in this town?] IF YES: How or in what ways; IF NO: Why do you think it doesn't?

62. How do you think ABC could be changed for the better?

V. GENERAL COMMENTS ABOUT THE SYSTEM AND FUTURE IDEAS OR DREAMS FOR CHANGE

63. Have you had problems in this community that you see as related to your emotional problems? IF YES: What kind of problems have you had?
64. Do you have ideas about the "ideal" community for people having emotional problems? What are some things--or programs--that a community could offer that would help someone with emotional problems?
65. Now that you've told me some of the good points and bad points about programs you've been involved with, can you describe--in general or over-all --what you think are the characteristics that make the good programs good or bad programs bad?

66. Are there ways in which you think these good characteristics could be added to existing programs? (OR what needs to be changed in the bad programs to make them good?)
67. Is there a way you could summarize (or add to what you've said about) what benefits you've gained from your involvement with ABC ? Can you summarize (or describe) what disadvantages there might be for you or others involved with ABC ?
68. Do you have ideas for in-patient programs that would help someone hospitalized for the first time?
69. Do you have ideas for after-care/ out-patient community-based programs that would facilitate recovery from emotional problems?
70. Do you have thoughts about ways to remove the factors you've identified as affecting treatment from the system? (You've said that ___________ [gender, racial and/or ethnic, sexual preference, intelligence level, others] affects some people's care...How do you think that can be changed?)
71. Anything else you want to add? Something you wished I had asked, but didn't?

APPENDIX B

Recruitment Tape Transcription

September, 1987

Hi. This is Taffy [Marion] McCoy and I want to explain a research project I'm doing for MSU that I hope you'll want to be a part of. I will explain the project in this tape, then if you're interested in being interviewed for it, [the ABC Employee who volunteered to help with recruitment] will give you a consent form to sign. Signing the form means: you want to be interviewed; and you understand what the interviews will be about.

Now back to the project. I'm working on my Ph. D. in sociology and for it I need to do some research and write a long paper about it, called a dissertation. What I'm asking you to do--if you want to--is agree to do an interview with me. In the interview, I'll ask you questions about things in 4 areas: 1) your current situation in the mental health system; 2) some details about your past psych history--hospital experiences, therapy experiences, and so on; 3) questions about your relationship to [ABC]--how you found out about it, what you do here, how long you've been in contact with it, etc. and 4) your ideas about what needs to be changed in the system--if anything--to make it better. In the last area, I'll also ask you to tell me the good points and bad points you see about [ABC] and other kinds of treatments or programs you've been involved with as a consumer in the system.

Some of my questions about your past may bring back sad or painful memories. We may talk about things that you did or saw that were illegal (like using street drugs in the hospital) or dangerous (like making or using weapons in the hospital). It is important that you know you don't have to answer any question you don't want to and that anything you do tell me will be kept in confidence. I will tape the interviews and may take notes, too, but your identity will ALWAYS be kept secret if or when I use information from your interview in my paper.

I need you to be as open and honest with me as you can and feel comfortable doing. This is because I want to document how things ACTUALLY are for consumers in the system. I also want you to tell me how your hospital experiences and out-patient programs REALLY were for you--did anything help you? Were there things that set you back or made you feel worse? I also want to know about [ABC]--are there things that happen here that aren't good for you? And if you see good things here, can you tell me why you think they work? These are the kinds of issues I want to raise in the interview with you.

Just a couple of other things. I don't want you to feel pressured into doing an interview if you don't want to. That's the reason I'm taping this--so you can decide if you really want to or not. I won't even know who asks [the ABC employee who helped recruit] to hear this tape until I get a signed consent form. There are only a few reasons I might not interview you if you sign up--like if I get too many volunteers. I need to be sure to interview a mixture of men and women, different ages and so on. Also, MSU will not permit me to interview people who have guardians or who are in the hospital.

Because I want to talk about many things, the interviews may take 2-3 hours or more, but we can break that down into 1-hour segments if you like. After we're finished, I want to thank you in some real way, either by paying you $15.00 for the interview or taking you out to dinner, according to what you'd like more. We can talk more about those arrangements when we meet to do the interview.

If you have more questions about the interview, please ask [the ABC employee helping with recruitment] who will be able to answer them and/or pass them along to me and we'll see that you get the information you need. If you feel clear about your decision to sign up now, [the ABC employee helping with recruitment] has a consent form you can sign. If you do sign up, please let me know how to get a hold of you so that we can arrange a time for the interview.

Thanks for your interest--and for listening to this tape! Hope to see you soon.

APPENDIX C

Consent Form

Michigan State University, Department of Sociology

1. I have agreed to take part in a research project being conducted by Taffy (Marion) Mc Coy, a sociology graduate student, under the supervision of Dr. [Barrie Thorne], her school advisor at MSU. This study also has the approval and cooperation of [Executive Director of the consumer-run organization].

2. I understand that this research concerns the experiences of mental health care consumers, and consumers' opinions about the kinds of mental health care they have received or been part of.

3. I understand that this interview may take 2-3 hours, but will be done in 2 or 3 parts, with no part taking longer than one hour. I know that the interview will be about my experiences in the mental health care system, and about my opinions of specific mental health care programs.

4. I know that some of the things I am asked about in the interview may bring back sad memories and/or deal with feelings or activities that I am sensitive about. I know that I don't have to answer any question I don't want to answer, and I can stop the interview at any time without penalty. I know that anything I say in the interview will be kept in absolute confidence, and I will remain anonymous.

5. I know the interview will be taped and notes will be taken on what I say. I know that only Taffy Mc Coy will hear these tapes, and that after the tapes are transcribed, they will be erased. I also understand that Dr. Barrie Thorne (Taffy's school advisor) may see notes about the interview, but won't know who was interviewed if she does.

6. I understand that portions of the interview will be included in the final report of the research project, but that my identity will be kept in confidence and I will remain anonymous.

7. I am aware that Taffy Mc Coy did research here in 1983, and may have observed me then when she took notes on interactions in the organization's office. I understand that she may use these notes in her final paper, but that my identity will be kept in confidence and I will remain anonymous.

8. I understand that further explanation of the research and/or the final results of the study will be made available to me if I request it.

9. I understand that my participation in the research does not guarantee any beneficial results to me.

I have read and understand this consent form:

____

(Signature) (Date)