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THE CONSUMER/SURVIVOR MOVEMENT: A PARADIGM SHIFT IN THE CARE
OF THE MENTALLY ILL

submitted in partial fulfillment of the requirements for the degree of Bachelor of Arts in Liberal Studies in the School for Summer and Continuing Education of Georgetown University has been read and approved.

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Date
THE CONSUMER/SURVIVOR MOVEMENT: 
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A Thesis
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By

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ABSTRACT  

The purpose of this paper is to examine the shift in philosophy in the mental health community from the traditional model to the consumer/survivor model. I have traced the history of formal mental health care in this country; from the opening of the first psychiatric hospital in 1773 through the deinstitutionalization policy in the 1960s. There was little change in the approach to care in spite of the change of venue. Since deinstitutionalization, a recognition of the capabilities of consumers/survivors has evolved. Mental health reform has been influenced by several factors including, growth of the consumer movement and the recognition that persons with mental illness benefit from community life. The new model is based on the ideas of empowerment and community reintegration. Two areas where the paradigm change has been successful are clubhouses and housing with supports.  

My research was obtained from books, journals and program literature from local clubhouse programs. I also did some field work in a community residence. The role of the staff was to encourage personal choices and personal responsibility. This allowed me to gain firsthand knowledge from people who have advocated or have been directly affected by the paradigm change. All consumers need to be more involved in decisions
affecting their lives, such as their medications, physicians, and housing. Though the consumer/survivor movement is not yet the prevailing paradigm, I will illustrate the positive progress of the movement. I will also discuss the human values element of this movement.
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Introduction

There is a movement toward a shift in the philosophy and practice in the mental health community, from the traditional model to the consumer/survivor movement model. The new model is based on the ideas of choice, empowerment, and community reintegration. My thesis will propose that patients are better served by the shifted focus from institutionalized type care to personal responsibility and self determination. I will explore the history and evolution of care of the mentally ill in the United States. I will look at two areas where the paradigm change has been successful, clubhouses and housing with supports.

The clubhouse represents a programmatic change from traditional clinic care to a psycho-social rehabilitation model. Clubhouses provide services, such as job training and counseling sessions, as a traditional clinic would. However, consumers, meaning consumers of mental health services, are actively involved in running clubhouses. Consumers are able to socialize and participate in activities. Many clubhouses are peer run, promoting recovery by developing a social and support network. This network provides self-help and empowerment services, such as mutual support groups, empowerment training and consumer run community projects. This model has been successful because the focus is on wellness rather than illness.

The second area where the change has been successful is a shift from the
community residence (CR) to housing with supports. The CR is often identified with retrofitting mental health services in relation to where one lives. This retrofitting should no longer be the norm. Choosing one’s own housing and available services is a viable, humane solution back to the community. That is what the housing with supports model advocates.

My thesis is at its core a human values issue. It explores freedom of choice and self-determination, or lack there of, and the role it plays in recovery and integration. The consumer/survivor movement promotes the autonomy of the individual. A goal of this movement is restoring full citizenship to persons with mental illness. “...psychosocial rehabilitation is a process of restitution, reconstruction, and construction of the political, legal, and societal rights of every citizen” (Saraceno 1997). Many consumers were used to long-term inpatient facilities where their choices were made for them by mental health care professionals, not the consumers themselves. By not making choices for themselves, consumers were being denied a basic human right (Cella et al. 1997).

I will explore the motivation for change, implementation, and results of the shift in paradigm. I intend to argue that the model changes are successful, positive, and a step forward.
Chapter One

History of Institutional Care

The Eastern Lunatic Asylum of Williamsburg, Virginia, which opened in 1773, was the first psychiatric hospital in the United States. The hospital contained twenty beds. It was not until after 1800, that all the beds were filled. Thirty three years later a second hospital opened in Baltimore. Others in Boston, New York and Philadelphia soon followed. Thus began the era of institutional confinement for the mentally ill. This type of care would last approximately 150 years.

Public psychiatric hospitals were built with a humanitarian approach to care in mind. This came to be known as “moral treatment” (Johnson 1990). The Eastern Asylum was one of the pioneering institutions of this approach. The theory behind moral treatment was the belief, “that mental patients could learn behavioral self-control through a corrective relationship with a benign authority figure. . . ” (Johnson 1990). The proponents of moral treatment expected their regimen would cure mental illness, not just separate the mentally ill from society. “Moral treatment assumed a close personal relationship between each patient and the superintendent of the asylum, which itself had to be small and to provide a pleasant environment” (Johnson 1990). In this atmosphere, non-symptomatic and restrained behavior was rewarded. The patients were treated as rational people.
The superintendents controlled all aspects of the asylum, most importantly admissions. "... they tended to choose patients who came from affluent families, and to admit no more than 200 to 250 patients..." (Johnson 1990). Moral treatment was successful in terms of discharge and lack of reinstitutionalization. For example, "the Bloomington Asylum admitted 1,841 patients between 1821 and 1844... 1,762 were discharged, including 672 cured, 104 much improved, and 328 improved; cure was defined as minimal function within both the patient's family and society at large" (Johnson 1990).

The model of moral treatment in asylums was widely copied. Private institutions began to incorporate the beliefs of moral treatment in keeping with the founders of the approach. With the successes of these asylums, the idea that asylum care cured mental illness flourished. It was thought that mental illness was caused by lesions in the brain exacerbated by stress and instability. The asylum strived to create a community where a patient could relearn daily living skills without the stressors of society.

There was a steady growth of chronic mentally ill patients, who did not respond to treatment. The existence of these incurable patients challenged the main tenet of moral treatment, successful treatment of the mentally ill. For the chronically ill, the claims of cure are unfounded. They needed an alternative to the moral treatment model.
State Hospitals

State hospitals, created in the mid-nineteenth century, were the answer for the chronic mentally ill. These individuals were, "... alcoholics, people with dangerous behavior problems, deranged individuals who had been rejected by the almshouses, and most particularly the senile elderly..." (Johnson 1990). Thus the number of patients in public facilities continued to grow. This population also posed two clinical predicaments, which still exist. "First, the only known treatment models have been generally been geared toward acute illness. ... Second, no acute care facility needed a lot of treatment failures around undermining the confidence of other patients or the staff in the very treatment they received or provided" (Johnson 1990). The chronic mentally ill person is too sick to be released as either cured or improved.

By providing custodial care mental institutions were beneficial for communities, families of the mentally ill, and the patients. State hospitals found success and public acceptance in their early years. The state fulfilled its ethical and moral obligations in providing for the mentally ill. A psychiatrist remarked in 1852, on the founding of mental hospitals,

... the spread of their reports, the extension of the knowledge of their character, power and usefulness, by the means of the patients that they protect and cure, have created and continue to create, more and more interest in the subject of insanity, ... Consequently, more and more persons and families, who formerly kept their insane friends and relations at home now believe that they can be restored, or improved, or at least made more comfortable in these public institutions. (Grob 1983)
By 1800, there were approximately 140 public and private hospitals caring for roughly 41,000 patients. The majority of these patients were in public institutions. Almost every state had at least one mental hospital. Many states established more hospitals in order to provide access for those in need. Hospital admissions began to grow for two reasons, higher ceilings were placed on the patient intake and states slowed the pace of building new facilities. All patients were, theoretically, supposed to receive equal quality of care. However, factors such as race, class, and ethnicity determined patient care.

Nineteenth century hospitals were built according the Kirkbride Plan. The Kirkbride Plan was based on the innovative writings of Dr. Thomas Story Kirkbride, on hospital design and management. Dr. Kirkbride was the superintendent of the Pennsylvania Hospital for the Insane from 1841 to 1883. His plan was endorsed by the Association of Medical Superintendents of American Institutes for the Insane (AMSAII).

Most hospital grounds shared the following layout. The central building contained, “...the kitchen, store rooms, reception areas, business and medical offices, chapel, library, and living quarters for the medical officers” (Grob 1983). On either side were the patient wings, one for females the other for males. Similar structures could be built if additional accommodations were needed. Each wing was divided into wards for patients according to classification. The structure of the hospital reflected, “...prevailing psychiatric ideology: separation of patients from the community;
creation of a new therapeutic environment; the importance of classifying patients; the
dominant and controlling role of the psychiatrist-superintendent; and reassurance to the
family and community that patients would be cared for in a secure moral and medical
environment that would promote their comfort, happiness and even recovery” (Grob
1983).

The State Lunatic Asylum of Utica, New York, represented, in many respects, a
typical institution. The asylum housed just over 600 patients, in 1884; 2 percent of
whom slept on the floor as the patient population exceeded the bed capacity. The female
and male wings were divided into three departments. These departments were divided
into twelve wards populated according illness classification. The wards varied in size,
housing as few as 15 patients and as many as 40. The average was 27 patients per ward.
The female department consisted of:

   . . . two convalescent wards (one for mild cases of melancholia), two for
   quiet patients (including one for chronic cases), one for demented
   persons, one for melancholics, one for a mixed group; the remainder were
   for noisy and disturbed individuals. The men’s wing was organized in a
   comparable manner: one convalescent ward; five for quiet patients
   (including two for chronic cases); one for suicidal persons; and the
   remainder for demented, disturbed, or filthy patients. (Grob 1983)

The goal of the ward system was to keep together those patients who were least
likely to harm others and most likely to help each other. Appropriate classification of
patients was necessary to obtain this goal. Also important was proper treatment and care
of patients.
The future for an institutionalized person was not exceedingly promising in the late nineteenth century. The majority of hospitalized patients had long histories of disturbed behavior, and many had been institutionalized more than once. "After examining American and British statistics for a thirty year period, John B. Chapin estimated in 1877 that of every hundred cases, . . . 34 percent would recover by the end of one year, 29 percent would die, and 36 percent would remain at a stationary level" (Grob 1983). A portion of those who had recovered, would return to an institution as a result of relapse. In spite of their goals for rehabilitation and therapy, mental hospitals were actually providing long-term custodial care for many of their patients (Grob 1983).

State Hospital as Bureaucracy

State hospitals had to centralize and bureaucratize in order to control the growing number of patients and their costs. "The state hospital system was governed by a regulatory system that focused on what it could monitor—namely, order and efficiency, rather than the uniform treatment methods that the small asylums had stood for. . . ." (Johnson 1990).

New York was the first state to centralize their asylums, with the creation of State Commissioner of Lunacy office in 1873. The first commissioner worked to pass legislation in New York that required all patients in county facilities transferred to
centralized state facilities. This act, known as the State Care Act, became a model for the rest of the country.

By the 1870s, state institutions had organized themselves in the form they would retain for nearly one hundred years. The job of the superintendents was originally intended to be defined in medical terms. What they became, however, were hospital administrators preoccupied with managerial issues.

A typical hospital was organized with a hierarchy of authority. At the top was the superintendent. They approved all decisions effecting hospital care, including treatment, care, and any structural changes to the hospital. The assistant physicians were directly under the superintendents. They oversaw the departments and wards, as well as the daily care of patients. Most hospitals also had a number of nonmedical employees to take care of administrative functions, such as, preparing meals, maintenance on the hospital, and processing paperwork.

Nurses and attendants were at the bottom of the hierarchy. This group remained in constant contact with the patient population. Low wages and long hours made for high turnover rates in their positions. Some efforts were made to upgrade the skills of nurses and attendants, who often, had to deal with difficult patients. Some institutions began training schools. The McLean Hospital, an asylum affiliated with Massachusetts General Hospital, opened the first training school in 1882. This schools, and other that opened later, provided staff with structured course study. This included lectures and
supplemental readings. This differed from just receiving on-the-job-training, which was previously the norm. At the end of two years, students received a diploma, which in turn, would lead to the possibility of higher pay and a promotion. The efforts to upgrade staff were not met with overwhelming success, turnover still remained high.

The staff, both medical and administrative, shared the same goal; to serve the patient’s needs so that they may recover. However, this goal was rarely actualized. “As with virtually all human institutions, the ability to control the environment was severely restricted by both internal and external constraints. What emerged instead was an institution that reflected the human condition, with all of its strengths and weaknesses” (Grob 1983).

American Psychiatry

The science of psychiatry, began in and was associated with institutions. Private practice was virtually nonexistant in the nineteenth century. Unlike other physicians, who kept a private practice while affiliated with hospitals, psychiatrists did not. Their expertise lay in the institutionalized patient. Most psychiatrists were public employees.

Most physicians received no exposure to mental illness during their training, even those who decided to specialize in psychiatry. Their first introduction to the world of mental illness usually occurred when they became an assistant physician in an
institution. As a result, psychiatry, in thought and practice, was molded by the institutional setting and experience. "Explanations of the etiology, symptoms, and prognosis of mental disease reflected not only the social background and medical training of physicians, but their experiences within mental hospitals" (Grob 1983).

Early on, psychiatrists and the rest of the medical world shared similar positions on health and the nature of disease. Toward the end of the nineteenth century however, medicine and psychiatry began to follow dissimilar paths. In the 1880's, non-psychiatric hospitals, began to take their modern form. The authority shifted from trustees to physicians. "This trend mirrored the transformation of the general hospital from an institution providing care for socially marginal groups to one reflecting a new emphasis on science and technology and catering to more affluent groups capable of paying the high costs involved" (Grob 1983). Physicians began to talk of medicine as a biologically oriented science. Health and disease were viewed differently. The future of medicine would lie in science and technology.

Psychiatry did not undergo such radical changes. Thus, institutional psychiatry and mental hospital as relief-instituion seemed distant from mainstream medicine. This distance would ultimately serve to make psychiatrists aware of innovations that would change the nature and location of their medicine.
In the late nineteenth century, psychiatrists were under attack from a variety of sources, including, social activists, lawyers, former patients, and state regulatory agencies. Former patients claimed they had been treated too severely or had been committed illegally. Former patients and their supporters sought to reform the hospitals, not abolish them. As a result of their crusading, many states passed legislation that protected patients rights and reduced the authority of hospital officials. “Some states established visiting committees with powers to inquire into conditions at mental hospitals. . . . The first law giving patients letter-writing rights without any censorship was passed in Iowa in 1872 . . .” (Grob 1983). Most hospital superintendents viewed the legislation negatively. They felt such legislation undermined their professional autonomy as well as their proficiency as physicians.

The ferment about patients rights and attacks on institutional care, paved the way for the creation of the National Association for the Protection of the Insane and the Prevention of Insanity in 1880. Initially, the group was received warmly by both the medical and lay circles. Some hospital psychiatrists joined the association. They held meetings and, in 1883, began to publish the American Psychological Journal. However by 1884, the organization no longer existed. Growing dissent between institution superintendents and their critics led to rifts in the organization. Before the organization finally dissolved, several of the group founders had either died or resigned.
By the 1890’s, psychiatry was undergoing a transformation largely due to mounting criticism in the past two decades. Early psychiatrists made the care of the institutionalized patients a priority, through emphasis on managerial and administrative aspects of the hospital. The late nineteenth century view was as much concerned with mental illness as a disease as they were with the individuals; in time the former replaced the latter. Another significant change was the development of the mental hospital as enemy. “Institutional psychiatry thus came to represent the past, and the new ‘scientific’ psychiatry the future” (Grob 1983). The dissatisfaction with the mental hospital, paved the way for the emergence of private practice and outpatient work. “The result was the beginnings of an implicit abandonment of institutionalized patients. . .” (Grob 1983).

Mental Hygiene Movement

The unrest in the psychiatric community helped to lay the groundwork for what became the Mental Hygiene movement. Mental hygiene was a union of science and social activism. This movement also reflected a confidence in the human ability to prevent disease and other social ills.

The commitment to mental hygiene saw the creation of several organizations, including the National Committee for Mental Hygiene (NCMH). The goals of this organization were, “. . . protect the public’s mental health; promote research into and dissemination of material pertaining to the etiology, treatment, and prevention of mental
disease; enlist the aid of the federal government; and establish state societies for mental
hygiene” (Grob 1983). The NCMH is invariably linked with Clifford W. Beers.

In 1900, after a failed suicide attempt, Beers’s family admitted him to Stamford
Hall. This small, private institution specialized in treating mental disorders, and
addictions, such as alcohol or opiate. After eight months, his family could no longer
afford the costs of a private institution. Beers was next sent to the Connecticut Hospital
for the Insane. After three years, he was discharged. His experience with mental
institutions gave rise to a belief that the system was in dire need of change if they were
to succeed in helping people.

He decided to write a book that would help those struggling with mental illness.
Beers intended to create a movement that would help thousands by improving the
conditions in mental hospitals. He began to write his autobiography, later titled *A Mind
That Found Itself*. William James, the philosopher and psychologist, provided Beers
with both moral and financial support; until James’ death in 1910. Beers sent his
manuscript to many psychiatrists for comment. “Since the book was indissolubly
linked to the creation of an organization, he did not wish to alienate a group whose
support he deemed vital” (Grob 1983).

In 1908, *A Mind That Found Itself* was published. Beer’s book received instant
praise both in the United States and overseas. The work, “... combined the desire to
expose, reform, and inform without ever denying the fact that the author had been
mentally ill” (Grob 1983). The book did not specifically attack mental institutions. Rather, it focused on the often harsh or insensitive treatment of the patients. *A Mind That Found Itself* was a call to initiate change in institutional care and the treatment of the mentally ill. The mental hygiene movement did not prove a victory for institutionalized patients. The population in state mental hospitals drastically increased, from 150,000 to 445,000 patients, between 1903 and 1940. In fact, the NCMH, set up to improve hospital conditions, became advocates for other groups, thus losing sight of their original goals. Mental hygiene succeeded in creating the NCMH, but mental hygiene also fed a nascent eugenics movement. These two movements, though different in philosophy, illustrate the receptivity of psychiatrists to new social roles and an effort to apply administrative solutions to prevent the proliferation of such groups as the mentally ill and the mentally retarded.

**Early Treatments**

What were the mental hygienists protesting? There was little hope for institutionalized mentally ill patients in the late nineteenth and into the early twentieth centuries. Patients were often put in dark, padded cells and usually restrained in straight jackets at night. They were beaten and choked by attendants. The mental hygiene movement made the public aware of these terrible conditions, but change was difficult. Mental institutions continued to stand separate from the rest of the medical world.
Treatment in nineteenth century hospitals tended to be eclectic and nonspecific. The institution superintendents were more inclined to pattern treatments according to older or more traditional medical procedures, "... given the absence of empirical data that might relate etiology, symptomatology, and physiology" (Grob 1983). The aim of treatment was to bring back the natural balance between the individual and their environment. "Therapy included a balanced diet that would rebuild the digestive tract and nervous system, a healthful environment, exercise, fresh air, sunlight, as well as the use of tonics and cathartics" (Grob 1983). In the mid-1890’s, experimental therapies began attracting some popularity. Thyroid extraction and the administration of electricity were used as treatments for mental disorders. Hospitals were also attracted to drug therapy, especially those drugs that could calm noisy and difficult patients; whose behavior tended to hinder their recovery as well as the recovery of others. Thus, a variety of sedatives and hypnotics were used. Some of the most common being, hyoscyamin, opium, morphine, bromine derivatives, chloral hydrate, paraldehyde, sulphonal, calomel, and digitalis.

The use of sedatives varied within the mental hospital system. "Some institutions spent two to three times as much for drugs as others; one or two expended five to six times the state average" (Grob 1983). The decision to medicate patients was made solely by the medical staff, family members were not consulted. Patients were not informed about their medication regimen. Often times the goal of medication was to
calm troublesome patients so as to, “facilitate the efficient management of a complex social institution. Faced with managerial problems that were related to disruptive behavior of patients, a substantial number of superintendents turned to medication as a palliative” (Grob 1983).

There was neither an effective treatment nor a known cause for mental illness, at that time. George Beard, an American neurologist, promoted the term neurasthenia in the 1800’s. This term applied to myriad physical ailments, today associated with depression. His definition of neurasthenia was, “. . . a chronic, functional disease of the nervous system, the basis of which is impoverishment of nervous force, waste of nerve-tissue in excess of repair. . .” (Valenstein 1986).

If the cause of neurasthenia was nervous exhaustion, then the logical treatment would be to reactivate the nervous system. Wilhelm Erb, a German neurologist, developed electrotherapy, which became widespread. A negative charge, cathode, was applied to the body to excite the nerves and a positive charge, anode, was used to sedate.

A competing therapy for neurasthenia at the time was hydrotherapy. This treatment dealt with the, “. . . various therapeutic effects of baths, douches, wet packs, steam, spritzers, and hoses” (Valenstein 1986). These treatments in no way prepared patients to leave a institution. Physicians and neurologists were seeking answers for the causes of mental illness.
Eugenics

There was a fear that mental illness and general degeneracy threatened the well being of the American people. As a result, drastic measures, such as marriage regulation, immigration control, and involuntary sterilization were supported. Eugenicists of the late nineteenth century were on a mission to promote the proliferation of the “fit” and to discourage the multiplication of the “unfit,”

In a society whose foundations seemed threatened by social tensions related to economic depressions, class conflict, rising levels of violence, and bureaucratically structured organizations whose activities seemed to submerge individual achievement, eugenicists offered an explanation and a guide to remedial action. (Grob 1983)

Connecticut, in 1896, was the first state to regulate marriage based on eugenic principles; other states soon followed with similar legislation. These early laws outlawed marriage between insane persons. However, eugenicists realized that such marriage laws would have a limited effect.

Marriage laws alone could not prevent sexual encounters that lead to pregnancy. Sterilization provided a solution, “. . . it was inexpensive, simple and relatively safe, irreversible in nature, and its benefits were clear and direct” (Grob 1983). For activists concerned about the prosperity of the American people, the case for sterilization was strong; the individual was in little danger and it was being done for the greater good of society.
Indiana passed the first sterilization laws in 1907. Confirmed criminals, idiots, imbeciles and rapists were subject to mandatory sterilization if recommended by a panel of experts. The next ten years saw about fifteen other states adopting similar legislation. Most of these laws applied to the mentally ill, as they were viewed as genetically undesirable. “By 1940 a total of thirty states had enacted at one time or another statutes that provided for the sterilization of individuals confined in state institutions” (Grob 1983). A total of 18,552 mentally ill living in state hospitals were surgically sterilized between 1907 and 1940. Institutionalized patients were in no position to protest. The groundwork was being laid for a major policy shift.
Chapter Two

Paving the Way for Deinstitutionalization

The American Medical Association (AMA) decided, in 1931, to formulate an official policy on the institutional care of insane persons. A research panel was formed, headed by John Maurice Grimes. Grimes was a physician, but not a psychiatrist. The American Psychiatric Association strongly objected to this study at first. They claimed the AMA was invading their territory; the AMA pressed on, motivated by the rampant rumors of mistreatment of patients under institutional care.

Grimes and his team visited 600 of the 631 the existing state mental hospitals. They distributed a survey to hospital directors, and received a surprising 75 percent return. The data collected from the visits and survey led Grimes to the conclusion that hospital conditions were disgraceful.

Grimes’ preliminary report of his findings was subject to radical revision (Johnson 1990) and he was subsequently fired before a final report could be written. An official final report was eventually written, by someone not affiliated with Grimes or his team, based entirely on the questionnaire data. The hospital visitation data was not included, firsthand information about the hospitals was ignored.

Grimes published his committee’s finding independently. According to Grimes, mental hospitals were overcrowded, and patients had nothing to do save working for the
hospital staff. The staff-patient ratio ranged anywhere from one to six to one to twenty six. Grimes contended that patients were kept locked up to reduce staff numbers and to keep the wards under control. There were more discoveries that were as provocative,

...Grimes was particularly offended by the use of terms like patient and hospital to describe a setting that merely housed neglected, chronically disordered people; he considered the attendants no more than "guards"...Grimes observed that "a mental hospital, to be called a hospital must cure its patients"... The states preferred to complain rather than update and improve their antiquated methods of care. (Johnson 1990)

Grimes proposed a policy of de-institutionalization, a vatic recommendation. His policy would see the immediate release of all appropriate patients, not to include those diagnosed with severe chronic mental illness, to aftercare clinics. Patients would be under the care of social workers and medical professionals. Grimes had other suggestions which included:

...conversion of all state hospitals to acute-care facilities run on the model of medicine, not on that of corrections; renovation of existing chronic-care wards to promote the aggressive training of long-term patients in the skills of daily living and work with an eye for their eventual discharge; and development of better ties between hospitals and the communities in which the patients had lived prior to admission. (Johnson 1990)

Unfortunately, the policy of deinstitutionalization originally adopted in the United States, was far from the one Grimes had proposed.
Era of Deinsituionalization

Deinsituionalization began over thirty years ago. This social process and ideology has dominated the mental health long-term care policy since it implementation. Deinsituionalization maintains that it is desirable, where possible, that, “...psychiatric patients live independently, assume responsibility for themselves, and try to adapt to the community” (Sands 1984). In order for this process to succeed two elements are essential: “(1) avoidance of the placement of psychiatric patients in institutions and (2) expansion of community services that will enable those persons to remain in the community” (Sands 1984).

In the decades following World War II, the necessity of mental institutions was under scrutiny. Deinstitutionalization was a manifestation of the attacks against institutional care. A 1961 report from the Joint Commission on Mental Illness and Health proposed that no new mental hospitals be built. The report also stated that any hospital with more than one thousand beds, “...should be gradually and progressively converted into centers for the long-term and combined care of chronic diseases, including mental illness” (Johnson 1990). The report was not predicting things to come, rather it was a reflection of the movement away from hospitalization.

Patient population had exceeded a half million by the mid-1950s. It peaked in 1955, then began to decline. Between 1960 and 1975, total population fell from 536,000 to 193,000 (Grob 1983). Patients were discharged into communities that were either
unwilling or unready to cope with them. The mentally ill fell victim to a policy that was supposedly meant to benefit them.

There were myriad factors that propelled deinstitutionalization. States began to realize that long-term care of mentally ill persons was cost prohibitive. As a result of rising costs, states felt they could not provide the needed care for the patient population. Mental health costs, unlike education, welfare, and highways, were not subsidized by the federal government. Federal aid was not the sole goal of state governments. State officials felt, "...there are many persons in state hospitals who are not now in need of continuing psychiatric hospital care. Outpatient clinics should be extended and other community resources developed to care for persons in need of help, but not of hospitalization" (Johnson 1990).

The introduction and wide distribution of psychotropic medication was another factor leading to a deinstitutionalization policy in the United States. In 1954, chlorpromazine, a new tranquilizing drug, received approval of the FDA. State hospital physicians were pleased with the results they saw when chlorpromazine was introduced to the patient population. Psychotics had the ability to control many symptoms of mental disorders. Medication was at an advantage over previous treatments, electroconculsive therapy or lobotomy for example, as it could be used easily in extramural settings. The use of this medication produced more manageable patients,
which in turn, encouraged more positive attitudes about releasing patients back into
society.

The easiest patients to place after discharge, were those who had families to go
back to and who were willing to be involved in their care. This was the case of the first
wave of patients leaving hospitals in the mid-1950s; 65 percent of them had families to
whom they returned. However by the mid-1970s, the percentage was significantly
reduced (Johnson 1990).

The successes of deinstitutionalization were limited. Long-term hospital
residents were released into communities without alternatives to institutional care.
Released patients often found themselves living in nursing homes or boarding houses.
The creation of a homeless mentally ill population also resulted from the shift out of the
hospitals. They were discharged without services, such as case management or day
programs. Medication compliance was another problem. Patients were unaccustomed
to self-medicating, and symptoms reappeared (Shadish et al. 1989).

Deinsitutionalization was born from concerns about social justice and human
rights. However, the results of deinstitutionalization did nothing to promote these
concerns. In many instances, patients were transferred from institution to institution and
eventually left in uncaring environments (Saraceno 1997). There are moral and ethical
repercussions in not providing adequate community care or supports for discharged
persons. "... 35% of people became homeless within 3 months of being discharged into
the community. . . . An increasing number of people requiring psychiatric care have become involved in the criminal justice system” (Lambie et al. 1997). Many consumers/survivors of mental health services were denied the opportunity to participate in community life. This led to the development of an array of innovations in the area of community support. The new service models, consumer/survivor movement for example, are unique in their recognition of the capacities of individual consumers/survivors (Trainor et al. 1997).
Chapter Three

Consumer/Survivor Movement

New approaches to community care arose in response to deinstitutionalization. The consumer/survivor movement is one approach. The focus of this model is on, “... an individual’s abilities as they relate to dealing with a particular illness and to living and working in the community” (Trainor et al. 1997). Individuals and organizations advocating the consumer/survivor movement, are seeking to improve upon the quality of life of individuals living with serious mental illness (SMI), for example schizophrenia or bipolar disorder (Fritz et al. 1998). Individual choice is one of the most important messages of the consumer/survivor movement. Consumers stress that when an individual is seeking treatment, the individual must be the key decision maker in developing an appropriate treatment plan. There is no one treatment plan that works for all persons living with mental illness.

Having a voice is a theme that runs through the movement and manifests itself in many ways; petitioning the government, both local and federal, and general advocacy are ways to have a voice. An individual’s personal experience with mental illness will direct the recommendations made to federal, state and county governments, or the managed care organizations that are responsible for designing and financing services and
programs used by consumers living with SMI. Individuals living with SMI and their family members often support and advocate very different philosophies and approaches, as a result of differences in experiences and opinions among consumer/survivors. The greatest area of debate among consumers include differing opinions on the causes of mental illness and choice of treatment, the use of medication versus other forms of treatment in the recovery process (Fritz et al. 1998). These same issues have led to controversy among consumers and families. Despite these differences, over the last two decades consumer/survivors have made progress in voicing their rights and motivating politicians, policy makers and providers to be more responsive to their needs (Fritz et al. 1998).

Another key element of consumer/survivor initiatives is empowerment. Empowerment incorporates some of the following qualities for the individual:

- Having decision-making power; having access to information and resources; having a range of options from which to make choices
- Assertiveness; not feeling alone, feeling part of a group; understanding that people have rights; effecting change in one’s life and community;
- Increasing one’s positive self-image and overcoming stigma. (Chamberlin 1997)

Within the scope of the above definition, empowerment is more of a process than a concept. Therefore, it is not necessary for the individual to display all the elements of empowerment in order to be empowered.

There is evidence that individual advocates vocalized the disparity in rights of people living with SMI as early as the 18th and 19th centuries- the proponents of moral
treatment, Clifford Beers, and the mental hygiene movement. The lineage of the consumer/survivor movement in its present incarnation, however, can be traced back to some key grassroots organizations of the 1970s. They include: the Insane Liberation Front, the Mental Patient’s Liberation Project, and the Network Against Psychiatric Assault. These groups were influenced by the black, women’s and gay liberation movements whose major organizing principles were self-determination and self definition. These consumer run organizations did not receive any federal or state funding to support their endeavors. The groups were successful in communicating and disseminating information through the founding of both the annual Conference on Human Rights and Psychiatric Oppression and the publication *Madness Network News* (Fritz et al. 1998). The first Conference was held in 1973 at the University of Detroit. Fifty people from across the United States and Canada met to discuss the emerging philosophies and goals of the liberation of persons with mental illness. Conferences were held annually through 1985 (Chamberlain 1990). The *Madness Network News* began in 1972 as a San Francisco area newsletter. Eventually, it developed into a newspaper that covered the consumer/survivor movement worldwide. It published personal experiences, art, creative writing, and factual reporting from a consumer point of view. *Madness Network News* ceased publication in 1986.

“The heart of the movement, however, continued to be the individual local group. . . . Most groups were started by a small number of people coalescing out of a
shared anger and a sense that through organization they could bring about change” (Chamberlin 1990). Each local group has developed their own ideologies, styles, and terminology to describe themselves and their work. Within the consumer/survivor movement today, there exists a diversified network of organizations. The National Empowerment Center, the Bazelon Center for Mental Health Law, and the National Mental Health Association are a few nationally recognized organizations advocating the consumer/survivor movement.

One way the goals of the consumer/survivor movement can be realized is through the creation of programs that promote a recovery model of care. There are several examples of successful mental health organizations. They share these common elements:

1. comprehensive series of services available as alternatives to inpatient hospitalization and a designated caregiver responsible for designing a treatment plan and coordinating services (case management). 2. Accessible, low cost, and appropriate housing options for the mentally ill. 3. Fiscal incentives and budgetary control for meeting client need and proving suitable and coast effective community care. (DiGirolamo 1996)

A comprehensive mental health system must also have the ability to fulfill three essential elements: treatment, rehabilitation, and support (Liberman 1997). Each element responds to specific clinical service needs. Treatment services help to control symptoms, eliminate illness and promote personal growth. This can be attained through psychotherapeutic and psychopharmacological interventions (Liberman, 1997).
Rehabilitation helps reduce or overcome hindrances which prevent the individual from performing daily life activities. Social supports help the individual maintain the advances achieved in treatment and rehabilitation. Clubhouses and housing with supports are two examples of programs where a recovery model of care has been implemented.

Clubhouses

The Community Support Services (CSS) model is in place in almost all of the states. This model, under which clubhouses fall, provides a community-based care system with, "... full range of outreach, treatment, rehabilitation, housing, life and social supports, crisis, and protection and advocacy services" (Blank et al. 1996). Here the needs of the individual are addressed. It also emphasizes the potential of these people and builds on their strengths and abilities (Blank et al. 1996). Within such a framework some of the goals of empowerment can be achieved.

The clubhouses provide such an environment. Clubhouses have many positive therapeutic essentials to offer, such as, group membership, normalization, daytime work, socialization, and the like (Blank et al. 1996). Recovery is dependent upon the specific "person-environment fit" between individuals referred for clubhouse services and the program milieu (Blank et al. 1996).

Clubhouses operate under codified standards that illustrate the philosophy and practice of the clubhouse model. There are "... 35 benchmarks for clubhouse operation
internally and within the larger community in the following domains: membership, relationships, space, work-ordered day, transitional and independent employment” (Blank et al. 1996). These standards were adopted to insure that mental health services were provided to consumers. One study done on four clubhouses in Virginia found, “. . . lower hospitalization rates were associated with greater program participation and that positive perceptions of program relationships were associated with higher levels of daily activities (a quality of life measure)” (Blank et al. 1996).

The criteria to join a clubhouse vary among the individual programs. Generally, they are meant for persons with a history of mental illness who have an interest in joining the clubhouse. Participants must be referred by a licensed mental health practitioner. An assessment is made as to whether or not the individual will benefit from a clubhouse program. Individuals who are too preoccupied with their symptoms to think about life goals, who view change as negative or impossible, or as a consequence of their illness do not have the basis to make decisions are not appropriate candidates for the clubhouse program.

Fountain House, Inc. is one example of a functioning clubhouse program. Their mission is in keeping with the tenets of the consumer/survivor movement. The mission of Fountain House is dedicated to the recovery of individuals with mental illness by providing opportunities to live, work, and learn, while contributing their talents through a community of mutual support (Fountain House Inc. 1997). Fountain House offers a
number of work and educational programs. Some of these include: an employment placement center, evening/weekend activities, substance abuse awareness project, and information and technology support. All the program activities are for both members and staff.

Followers of the clubhouse model understand that every person has something to contribute. Fountain House is an example of the clubhouse system. It provides a setting that is capable of accepting, valuing and using these contributions (Fountain House Inc. 1997). This setting is created by making sure that each member experiences a sense of ownership in the clubhouse, has a feeling of being wanted and needed by those who make up Fountain House (staff and members), and can recognize that their contributions are crucial to the function of the house (Fountain House Inc. 1997).

Fountain House in no way resembles an institution. It was expressly designed so that members enjoy visiting, and do not feel as if they are in hospital setting. The clubhouse is also set up to extend the feeling that the members are part of a large family.

Housing With Supports

I have chosen to look at one housing option in relation to consumer/survivor initiatives. A home is more than merely a shelter. A home can offer stability and the opportunity to create community, whether it is one’s own room, apartment, or house.
For people living with SMI, a home can be a place to live in dignity where recovery can take place.

For two years, I worked for a organization called Options for Community Living, Inc. (Options). Founded in 1982, Options is located throughout Suffolk County, New York. Their mission is committed to assisting individuals to develop the necessary daily life skills for independent living (Options Inc. 1998). They have two housing programs, community residences and permanent housing, both housing programs have supports. I will discuss the community residence program. The essential goal of supported housing is to contribute to or achieve the goal of psychiatric rehabilitation. The supports offered are designed to complement other forms of treatment, such as outpatient day programs, and community support.

Options has a number of community residences, which provide an alternative to hospitalization, nursing homes, or living alone at a boarding house. Residents live, learn, and develop their potential, i.e. realize the empowerment process, in an environment that respects individual choice (Options Inc. 1998). Level of care and length of stay depend in the individual’s needs and skills. Residents are given a case manager, who works in designated office space in the residence. As a part of the program, residents sit down with their counselor to define their goals and draw up a service plan. The service plan creates a strategy for completing each phase of the
rehabilitation process. Goal setting allows individuals to make informed decisions about environments in which they may work, socialize or learn, for example (Liberman 1997). In the Options program, most of the individual’s goals are achieved before they move on to independent housing.

Staff members are actively involved with residents in developing daily living skills (Options Inc. 1998). These include: setting up bank accounts, grocery shopping, personal grooming, and using public transportation. Residents are also made aware of available government services as well as existing groups that advocate rights for consumers, such as the National Alliance for the Mental Illness (NAMI).

Housing with supports is meant to complement other treatment programs. Residents of Options community residences must be enrolled in a treatment day program. Options counselors help in choosing a program that best fits the individual. At these day programs consumers can receive counseling, job training, attend group meetings, and learn medication management. State laws prohibit Options staff members from giving medication to residents. Staff and residents work together on medication management and compliance (Options Inc. 1998).

Each residence has a set of house rules. Residents are assigned weekly chores and there is a rotating cooking schedule. The environment, like Fountain House, in no way resembles a hospital. The environment is designed to be a home; a place where
residents feel they are part of a household, and take pride in the appearance and upkeep of the house (Options Inc. 1998).

In my experience, clients enjoyed the one-on-one interaction. A few of my clients remarked on how “normal” they felt when we would be chatting at the dinner table. One woman stated, in the hospital people did not really do too much talking. As the clients became acclimated the house environment clients took more initiative and needed less instruction. A current Options resident, who wished to remain anonymous, had this to say about the program, “It’s much nicer living here than with people who would look down on me because I had a mental illness. It’s so much different than before. I’m involved in better things, and I’m able to open up more. They encourage me to make my own decisions” (Doe 1999).

Both clubhouses and housing with supports are goal oriented programs. These types of programs are not for everyone. Individuals who need a structured program in order to live outside the hospital setting, do not thrive in the rehabilitation model of treatment. Their stabilization is based on the structure, activities, and relationships of their hospital setting. Rather these types of programs are for those who, “have become dissatisfied with their current life roles, relationships, and levels of community participation, and wish to make a change particularly in the areas of housing, work, education, and recreation” (Liberman 1997).
Both Fountain House and Options have adopted the philosophy and values of the consumer/survivor movement. The goal of staff and members is to achieve psychiatric rehabilitation, through community support and the individuals’ active role in their life. The federal government has shown an interest recently in consumer run self help programs. Funds have been allocated for a program study designed to gather more information on how consumer run programs contribute to the recovery and rehabilitation of individuals with mental illness. The study will also determine to what extent participation in such programs affects costs.

Since the 18th century, with the opening of the first asylum, patients had no input into the type of care they received. Mental institutions became largely custodial care institutions. Mental illness was taken out of the community and isolated. Deinstitutionalization provided the impetus for the shift in paradigm. Only in the past twenty years, has the trend been toward community reintegration. For the shift to be successful, there needs to be strong professional support, adequate housing, and community education.
Conclusion

There are two models of care for people living with SMI, the traditional model and the consumer/survivor model. "Institutional-medical models guided the early mental health systems, while an emphasis on psychosocial rehabilitation in community settings has been influential in the last two decades" (Lord et al. 1998). Early on in the history of mental health care, patients were often put into institutions, without their consent, by family members. The previous practice of extended hospitalization was based on the notion of people so consumed by illness and deficits as to need long-term, physical separation from regular society. Once institutionalized, hospital superintendents and staff controlled all aspects of the patients' lives. Patients, and families for the most part, were not consulted about treatment regimens. The hospitals determined which treatment programs would be appropriate. Patients had a passive role in their life and their recovery. This type of care dominated the mental health system until the early 1950's.

The next trend in mental health was deinstitutionalization, which falls under the traditional model of care. This policy grew from criticisms about poor and unjust treatment of hospitalized individuals. Deinstitutionalization did not work as it failed to adjust to changing needs and provide the necessary supports for people with mental illness. As a result, a revolving door was created. This describes a pattern where
patients repeatedly returned to the hospital (Lambie 1997). The result is a system that has not really changed. People living with SMI find themselves back in a hospital setting, with limited choice about their destiny.

Deinstitutionalization proved to be the impetus for a new model, the consumer/survivor model. Some of the most commonly shared objectives of those advocating the consumer movement include consciousness-raising through education, self-help, and civil rights advocacy. The growth of this movement reflects a change in values in the mental health care system. People living with SMI are encouraged to take a more active role in their lives and decisions that directly affect them. The greatest consensus among consumers is that each individual should have the right to make their own treatment choices. Having control over one’s destiny is part of the empowerment process, which in turn, is a part of the recovery process. Consumers/survivors, through choice and empowerment, are moving forward in making changes, “... in the way the general public, providers, and various health care delivery systems have traditionally perceived and provided services to individuals living with SMI” (Fritz 1998). The mental health care system is changing. It is moving beyond a service paradigm, to a system where consumers/survivors take action on their own behalf.

The consumer/survivor movement, though a step forward, is not yet the prevailing paradigm in mental health care. Across the country consumers, survivors, and
advocates work to pass legislation that promotes the civil rights of people with SMI, emphasizing freedom of choice. They have had some successes. In Oregon, for instance, persons with SMI are allowed to prepare a legal document, known as an advance directive. This document stipulates the mental health treatment the individual would like to receive should they lose their decision making capacity (Fritz 1998). Massachusetts also passed recent human rights legislation affecting persons with SMI. The law ensures individuals the right: to make and receive confidential phone calls, send and receive unopened, uncensored mail, and access to a humane psychological and physical environment. States should not have to pass laws that, “... mirror those already provided to all individuals in the constitution” (Fritz 1998). Under the Fourteenth Amendment’s equal protection clause, rights such as these should already be guaranteed along with all other rights that other citizens take for granted. With more awareness, education, and advocacy the consumer/survivor movement will emerge to become the prevailing paradigm.

The fundamental ideas behind consumer/survivor initiatives: freedom of choice, social justice, and individualism, are not unique to mental health. These are human values issues. As citizens of the United States, we should all be entitled to the same protection of our rights, without stigma or discrimination. These fundamental ideas have been the basis of other movements in our history, such as the civil rights movement and the women's movement. The ultimate goal of all these movements, including the
consumer/survivor movement, was and continues to be to gain full citizenship and to reintegrate individuals into the greater American community.
REFERENCES


