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The Ex-Patients' Movement: Where We've Been and Where We're Going

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The mental patients' liberation movement, which started in the early 1970s, is a political movement comprised of people who have experienced psychiatric treatment and hospitalization. Its two main goals are developing self-help alternatives to medically-based psychiatric treatment and securing full citizenship rights for people labeled "mentally ill." The movement questions the medical model of "mental illness," and insists that people who have been labeled as "mentally ill" speak on their own behalf and not be represented by others who claim to speak "for" them. The movement has developed its own philosophy, and operates a variety of self-help and mutual support programs in which ex-patients themselves control the services that are offered. Despite obstacles, the movement continues to grow and develop.

A complete history of the mental patients' liberation movement is still to be written. Like other liberation struggles of oppressed people, the activism of former psychiatric patients has been frequently ignored or discredited. Only when a group begins to emerge from subjugation can it begin to reclaim its own history. This process has been most fully developed in the black movement and the women's movement; it is in a less developed stage in the gay movement and the disability movement (of which the ex-patients' movement may be considered a part).

The "madman," as defined by others, is part of society's cultural heritage. Whether "madness" is explained by religious authorities (as demonic possession, for example), by secular authorities (as disturbance of the public order), or by medical authorities (as "mental illness"), the mad themselves have remained largely voiceless. The movement of people who call themselves variously, ex-patients, psychiatric inmates, and psychiatric survivors is an attempt to give voice to individuals who have been assumed to be irrational - to be "out of their minds."

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The ex-patients' movement began approximately in 1970, but we can trace its history back to many earlier former patients, in the late nineteenth and early twentieth centuries, who wrote stories of their mental hospital experiences and who attempted to change laws and public policies concerning the "insane." Thus, in 1868, Mrs. Elizabeth Packard published the first of several books and pamphlets in which she detailed her forced commitment by her husband in the Jacksonville (Illinois) Insane Asylum. She also founded the Anti-Insane Asylum Society, which apparently never became a viable organization (Dain, 1989). Similarly, in Massachusetts at about the same time, Elizabeth Stone, also committed by her husband, tried to rally public opinion to the cause of stopping the unjust incarceration of the "insane."

In the early part of this century, Clifford Beers, a wealthy young businessman, experienced several episodes of confused thinking and agitation which caused him to be placed in a mental hospital. Following his recovery, Beers (1953) wrote a book, *A Mind that Found Itself*, which went through numerous editions and which led to the formation of the influential National Committee on Mental Hygiene (later the National Association for Mental Health). Dain (1989) states that

. . . Beers was outspoken about abuse of mental patients and passionate in defending their rights and damning psychiatrists for tolerating mistreatment of patients. But he eventually toned down his hostility to psychiatry as it became obvious that for his reform movement to gain the support he sought at the highest levels of society it would have to include leading psychiatrists. Although he envisioned that eventually former mental patients and their families would be recruited into the movement, the public's persistent prejudice against mentally disturbed people and Beers' own doubts and inclinations, plus pressures from psychiatrists, drew him away from this goal. (pp. 9-10)

Dain also notes, in passing, the formation of the Alleged Lunatics' Friend Society in 1845 by former patients in England. On the whole, however, this early history is obscure, and the development of modern ex-patient groups in the United States at the beginning of the 1970s occurred primarily without any knowledge of these historical roots.

Although the terms have often been used interchangeably, "mental patients' liberation" (or "psychiatric inmates' liberation") and "anti-psychiatry" are not the same thing. "Anti-psychiatry" is largely an intellectual exercise of academics and dissident mental health professionals. There has been little attempt within anti-psychiatry to reach out to struggling ex-patients or to include their perspective. The focus in this paper is on ex-patient (or ex-inmate) groups. I identify the major principles that have guided the development of the ex-patients' movement, sketch the recent history of this movement, describe its major goals and accomplishments, and discuss the challenges facing it in this decade.

Stigma and discrimination still make it difficult for people to identify

themselves as ex-mental patients if they could otherwise pass as "normal," reinforcing public perceptions that the "bag lady" and the homeless drifter are representative of all former patients. Like the exemplary black persons of a generation or two ago — who were held to be "a credit to their race" and, by definition, atypical of black people generally — so the former mental patient who is successfully managing his or her life is widely seen as the exception that proves the rule.

Guiding Principles of the Movement

Exclusion of Non-Patients

In the United States, former patients have found that they work best when they exclude mental health professionals (and other non-patients) from their organizations (Chamberlin, 1987). There are several reasons why the movement has grown in this direction — a direction which began to develop in the early 1970s, influenced by the black, women's and gay liberation movements. Among the major organizing principles of these movements were self-definition and self-determination. Black people felt that white people could not truly understand their experiences; women felt similarly about men; homosexuals similarly about heterosexuals. As these groups evolved, they moved from defining themselves to setting their own priorities. To mental patients who began to organize, these principles seemed equally valid. Their own perceptions about "mental illness" were diametrically opposed to those of the general public, and even more so to those of mental health professionals. It seemed sensible, therefore, not to let non-patients into ex-patient organizations or to permit them to dictate an organization's goals.

There were also practical reasons for excluding non-patients. Those groups that did not exclude non-patients from membership almost always quickly dropped their liberation aspects and became reformist. In addition, such groups rapidly moved away from ex-patient control, with the tiny minority of non-patient members taking on leadership roles and setting future goals and directions. These experiences served as powerful examples to newly-forming ex-patient organizations that mixed membership was indeed destructive.

In attempting to solve these organizational problems, group members began to recognize a pattern they referred to as "mentalism" and "sane chauvinism," a set of assumptions which most people seemed to hold about mental patients: that they were incompetent, unable to do things for themselves, constantly in need of supervision and assistance, unpredictable, likely to be violent or irrational, and so forth. Not only did the general public express mentalist ideas; so did ex-patients themselves. These crippling stereotypes became recognized as a form of internalized oppression. The struggle against inter-

nalized oppression and mentalism generally was seen as best accomplished in groups composed exclusively of patients, through the process of consciousness-raising (borrowed from the women's movement).

Consciousness-Raising

The consciousness-raising process is one in which people share and examine their own experiences to learn about the contexts in which their lives are embedded. As used by the women's movement, consciousness-raising helped women to understand that matters of sexuality, marriage, divorce, job discrimination, roles, and so forth were not individual, personal problems but were instead indicators of society's systematic oppression of women. Similarly, as mental patients began to share their life stories, it became clear that distinct patterns of oppression existed and that our problems and difficulties were not solely internal and personal, as we had been told they were. The consciousness-raising process may be hampered by the presence of those who do not share common experiences (e.g., as women or as mental patients). As the necessity for consciousness-raising became more evident, it provided still another reason for limiting group membership.

Consciousness-raising is an ongoing process, with people and groups constantly recognizing deeper levels of oppression. Within an ex-patient group, various activities often lead to further consciousness-raising experiences. For example, a group may approach a local newspaper or television reporter to write a story about the group's work or to give its viewpoint on a current mental health issue. If the group's representatives are treated respectfully and their opinions listened to, no consciousness-raising issue arises. If, however, the reporter is unwilling to listen to the group's representatives or seems to disbelieve them or makes comments about their mental status, it can become an occasion for further consciousness-raising. Whereas, before the advent of the patients' liberation movement, the group might have altered its strategy or even disbanded after such a discouraging incident, armed with the knowledge that they have run into systematic discrimination they can decide how to proceed. They may complain to the reporter's superior. They may raise questions about discrimination against mental patients. Because of consciousness-raising, they will have a clear idea of what they are facing.

Historical Development of the Movement

Like many new developments in the United States, mental patients' liberation groups began primarily on the east and west coasts and then spread inland. Among the earliest groups were the Insane Liberation Front in Portland, Oregon (founded in 1970), the Mental Patients' Liberation Project

in New York City, the Mental Patients' Liberation Front in Boston (both founded in 1971), and the Network Against Psychiatric Assault in San Francisco (founded in 1972). Local groups took a long time to establish ongoing communications, because they were not funded and membership consisted mostly of low income individuals. The development of two major means of communication, the annual Conference on Human Rights and Psychiatric Oppression, and the San Francisco-based publication, *Madness Network News*, helped the movement to grow. Interestingly, both the Conference and *Madness Network News* began as mixed groups but later were operated and controlled solely by ex-patients (see below).

The first Conference on Human Rights and Psychiatric Oppression was held in 1973 at the University of Detroit, jointly sponsored by a sympathetic (non-patient) psychology professor and the New York City-based Mental Patients' Liberation Project (MPLP). Approximately fifty people from across the United States (and Canadian representatives) met for several days to discuss the developing philosophy and goals of mental patients' liberation. The leadership role of ex-patients was acknowledged; for example, the original name proposed by the sponsoring professor for the conference ("The Rights of the Mentally Disabled") was roundly rejected as stigmatizing. Although no plan was made in Detroit to continue the conference, the practice later developed of designating an attending group to sponsor the next year's conference. The conference became limited to patients and ex-patients only in 1976. Conferences were held annually through 1985 (see below for later developments).

Madness Network News began as a San Francisco-area newsletter in 1972 and gradually evolved into a newspaper format covering the ex-patients' movement in North America as well as worldwide. *Madness Network News'* original core group included both self-styled "radical" mental health professionals and ex-patients, but within a few years a major struggle ensued and the paper was published solely by ex-patients. There were also struggles between women and men ex-patients resulting in special women's issues edited by all-women, all-ex-patient staffs. *Madness Network News* existed solely on subscription income, which was sufficient to cover printing and mailing costs, but did not allow for salaries. For many years this publication was the voice of the American ex-patients' movement, a journal which published personal experiences, creative writing, art, political theory, and factual reporting, all from the ex-patient point of view. *Madness Network News* ceased publication in 1986.

The heart of the movement, however, continued to be the individual local group. Although some groups existed for only short periods, the overall number of groups continued to grow. 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. Groups were independent, loosely linked through *Madness Network News* and the annual Conference. Each

group developed its own ideologies, terminology, styles and goals. Groups were known by an astonishing variety of names, from the straightforward (Mental Patients' Alliance; Network Against Psychiatric Assault) to the euphemistic (Project Acceptance; Reclamation, Inc.). Some groups were organized as traditional hierarchies with officers and held formal meetings while other groups moved toward more egalitarian structures with shared decision-making and no formal leadership. Groups were united by certain rules and principles: mental health terminology was considered suspect; attitudes that limited opportunities for mental patients were to be discouraged and changed; and members' feelings – particularly feelings of anger toward the mental health system – were considered real and legitimate, not “symptoms of illness.”

The activities of various groups included organizing support groups, advocating for hospitalized patients, lobbying for changes in laws, public speaking, publishing newsletters, developing creative and artistic ways of dealing with the mental patient experience, etc. The two primary thrusts were advocacy and self-help alternatives to the psychiatric system, as it quickly became clear to each group that its own membership's needs largely fell into these two areas.

Different groups developed different terminologies to describe themselves and their work. “Ex-patient” was a controversial term because it appeared to embrace the medical model; *Madness Network News* promoted the use of “ex-psychiatric inmate,” which became widespread. Other groups referred to themselves as “clients,” “consumers,” or “psychiatric survivors.” Differences in terminology stressed differing emphases and priorities; clearly the individuals labelling themselves “inmates” or “survivors” took the more militant stance.

Because most groups existed with little or no outside funding they were limited in their accomplishments. The question of funding generated numerous controversies, as did the question of reimbursement for organizational labor. Even if the group decided it had no objection in principle to receiving outside funding, obtaining such funding was difficult. Potential funding sources tended to look askance on ex-patient groups – especially groups that rejected psychiatric ideology and terminology. Moreover, foundations which funded community organizing efforts did not view ex-patient groups as falling within their purview. Finally, state departments of mental health were seldom approached because of their role in running the very institutions in which group members had been oppressed. And those mental health departments that were approached were highly skeptical of the ability of ex-patient groups to run their own projects.

Gradually, however, inroads were made. Members of ex-patient groups demanded involvement in the various forums from which they were excluded – conferences, legislative hearings, boards, committees and the like. Although at first in only the most token numbers, ex-patients were slowly

invited to take part in such forums. Often groups had to insist on being invited, however.

Once involved in such meetings, ex-patients could move in two different tactical directions: cooperation or confrontation. Clearly, much was said in these forums which directly contradicted the movement's developing ideology. While most such meetings featured a reliance on psychiatric terminology and diagnosis, and on the assumption that patients existed in a lifetime dependency relationship, the patients' movement stood in opposition to the medical model and in support of self-reliance and self-determination. Although ex-patients' objections to such mentalist assumptions were often used as a reason to exclude ex-patients from future meetings, it is to the movement's credit that the ex-patients did speak up and object to much of what was being said. Frequently-heard objections from professional participants were that the ex-patients "polarized the discussion" or were "disruptive." Professionals sometimes chose to work with non-movement identified ex-patients who were much more likely to be compliant. For example, the most publicly visible post to go to an ex-patient in the 1970s — as one of the twenty-member President's Commission on Mental Health — went to a woman who had never worked with an ex-patient group but who had written about her patienthood experience in professional journals.

However, from this forum, as from others, the movement refused to be excluded. Movement activists packed many of the Commission's public hearings, testifying eloquently about the harmfulness of the psychiatric treatments they had experienced while pleading for enforcement of patients' rights and funding of patient-run alternatives to traditional treatment. The Commission's final report acknowledged the role of alternative treatments, stating that many of the latter "are wary of being classified as mental health services, convinced that such a classification entails a medical perspective and implies authoritarian relationships and derogatory labeling" ("Report," 1978, p. 14). The report went on to note that "groups composed of individuals with mental or emotional problems are in existence or are being formed all over the United States" (pp. 14-15).

The movement also demanded its inclusion in a series of conferences organized by the Community Support Program (CSP), a small division of the National Institute of Mental Health (NIMH). CSP, which began in the late 1970s, focused on providing assistance to programs in community settings. However, in the movement's view, these programs often perpetuated many of the worst features of institutionalization, including labeling, forced drug-ging, and paternalistic control. The participation of ex-patients in CSP conferences (even though the movement activists were vastly outnumbered by mental health professionals) forced CSP to acknowledge the importance of funding patient-run programs as a part of community support. Such recom-

mendations would not have been made – indeed, would not even have been considered – without the tenacity of movement activists who insisted on being heard.

Participation in professionally-sponsored conferences and meetings produced an additional unintended benefit. It enabled ex-patients to meet each other and learn from one another. Such contacts, especially by people from different geographical areas, were previously difficult but later became a source of inspiration and support during the exercise of an otherwise thankless task – to present the patient viewpoint to audiences that were often indifferent or even hostile toward that view.

Self-Help and Empowerment

Gradually, the movement began to put some of its principles into action in the operation of self-help programs as alternatives to professional treatment. Although the Mental Patients' Association (MPA) in Vancouver, Canada, began operating its drop-in center and residences within months of its founding in 1971, the first such projects did not appear in the United States until the late 1970s, largely because funding was unavailable.

Programs that developed out of the ex-patients' movement tend to be skeptical about the value of the mental health system and traditional psychiatric treatment (Chamberlin, Rogers, and Sneed, 1989). Members usually gravitate to these groups because they have had negative experiences in the system. Often, members are angry, and their anger is seen by the group as a healthy reaction to their experiences of abuse by the mental health system. At the same time, members, despite their distrust of the system, may simultaneously be involved in professionally-run programs. Members of user-run services are free to combine their participation in self-help groups with professionally-run services, in whatever proportion and combination each member determines.

Through successes experienced in self-help groups, members are enabled to take a stronger role in advocating for their own needs within the larger mental health system. Empowerment means that members have a voice in mental health matters generally – they reject the role of passive service recipient. Group members found themselves moving naturally into the role of advocate, representing the needs of clients on panels, boards, and committees. This may require accommodation on the part of other groups and group members such as administrators, policy makers, legislators, and family members, who typically have listened to everyone but the client about client needs.

Self-help groups do not exist in a vacuum. Even a group that sees itself as totally separate from the mental health system will, of necessity, have some

interactions with it, while groups that have been aided or brought into existence by mental health professionals will need to devise their own ways of making themselves autonomous from the larger system. By taking on a role other than that of the passive, needy client, self-help group members can change the systems with which they interact, as these systems adjust to respond to clients in their new roles as advocates and service providers.

Self-help is a concept, not a single program model. The concept is a means by which people become empowered and begin to think of themselves as competent individuals as they present themselves in new ways to the world. By its very nature, self-help combats stigma, because the negative images of mental patients ultimately must give way to the reality of clients managing their own lives and their own programs. The successes of self-help groups have been striking. Groups are handling annual budgets that may be in the hundreds of thousands of dollars; producing newsletters, books, and pamphlets; educating other clients and professionals about group work; influencing legislation and public policy; publicizing and advocating on their own behalf in the media; and, in general, challenging stereotypes and creating new realities. At the same time, individual group members may still be battling the particular manifestations that led to their being psychiatrically labeled in the first place. Self-help is not a miracle nor a cure-all, but it is a powerful confirmation that people, despite problems and disabilities, can achieve more than others (or they themselves) may have ever thought possible.

Advocacy

Self-help is one of two co-equal aspects of the ex-patients' movement; the other is advocacy, or working for political change. Unlike groups such as Recovery Inc. or Schizophrenics Anonymous, patient liberation groups tend to address problems that go beyond the individual. The basic principle of the movement is that all laws and practices which induce discrimination toward individuals who have been labeled "mentally ill" need to be changed, so that a psychiatric diagnosis has no more impact on a person's citizenship rights and responsibilities than does a diagnosis of diabetes or heart disease. To that end, all commitment laws, forced treatment laws, insanity defenses, and other similar practices should be abolished.

Ending involuntary treatment is a long-term goal of the patients' liberation movement. Meanwhile, movement activists work to improve conditions of people subjected to forced treatment, and to see that their existing rights are respected, keeping in mind that these are interim steps within a basically unjust system.

Existing laws have the power to compel people to receive treatment for mental illness. This almost never occurs in the case of physical illness, except in

the rare instances when courts overrule parents who refuse medical treatment for a child. The courts in these instances assume the *parens patriae* role, acting in lieu of parents in what the court defines as the child's best interest. When a person of whatever age is ordered by a court to undergo psychiatric treatment, this same *parens patriae* power comes into effect. This connection between the legal and medical systems places the mental patient at a disadvantage that is not faced by patients with physical illnesses.

In addition to the *parens patriae* doctrine, which assumes that a mentally ill individual is incapable of determining his or her own best interest, an additional doctrine, the police power of the state, is used to justify the involuntary confinement of individuals labeled mentally ill. This doctrine is based on the assumption that mentally ill people are dangerous and may do harm to themselves or to others if they are not confined. The belief in the dangerousness of the mentally ill is firmly rooted in our culture. It is especially promoted by the mass media, which frequently run stories in which crimes of violence are attributed to mental illness. If the alleged criminal has been previously hospitalized, the fact is prominently mentioned; if not, frequently a police officer or other authority figure will be quoted to the effect that the accused is "a mental case" or "a nut." In addition, unsolved crimes are often similarly attributed. Both the *parens patriae* power and the police power relate to the stereotyped view of the prospective patient — that he or she is sick, unpredictable, dangerous, unable to care for himself or herself, and unable to judge his or her own best interest.

The movement's advocacy has focused on the right of the individual *not* to be a patient, rather than on mere procedural safeguards before involuntary treatment can be instituted. A major lawsuit testing this right was filed by seven patients at Boston State Hospital in 1975, many of whom had been members of a patients' rights group that met weekly in the hospital with the aid of the Mental Patients' Liberation Front. The suit, originally known as *Rogers v. Macht*, was called, in later stages, *Rogers v. Okin* and *Rogers v. Commissioner of Mental Health* (1982). It established a limited right-to-refuse-treatment (i.e., psychiatric drugs) for Massachusetts patients.

Since *Rogers v. Commissioner*, right-to-refuse-treatment cases have been decided in a number of states, including New York (*Rivers v. Katz*, 1986) and California (*Reise v. St. Mary's Hospital*, 1987), and the right has been established administratively in some other states. While the movement first greeted these decisions as victories, it has become clear that, in practice, these reforms do little to change the power relationship between patient and psychiatrist. Each procedure (varying from state to state) provides one or more methods to override the patient's decision to refuse drugs; and whether the procedure is administrative or judicial, the end result is that most drug-refusing patients whose cases are heard are forced, ultimately, to take the drugs, despite the

ostensible right to refuse them (Appelbaum, 1988). Many movement activists have become discouraged and no longer believe that the courts will help people avoid involuntary patienthood through the mechanism of the right to refuse treatment.

Many individuals in the ex-patients' movement first encountered a critique of the mental health system — a critique which confirmed their feelings — in the works of Thomas Szasz. In such books as *The Myth of Mental Illness* (1961) and *The Manufacture of Madness* (1970), in a career spanning more than thirty years, Szasz has always spoken powerfully about the essential wrongness of forced psychiatric treatment, and the fallacy of defining social and behavioral problems as illnesses. In a recent paper, Szasz (1989) provides a devastating critique of the mental patients' "rights" movement, which has been guided largely by lawyers and non-patients.

Rallying to the battle cry of "civil rights for mental patients," professional civil libertarians, special-interest-mongering attorneys, and the relatives of mental patients joined conventional psychiatrists demanding rights for mental patients — *qua* mental patients. The result has been a perverse sort of affirmative action program: since mental patients are ill, they have a right to treatment; since many are homeless, they have a right to housing; and so it goes, generating even a special right to reject treatment (a right every non-mental patient has *without* special dispensation). In short, the phrase "rights of mental patients" has meant everything but according persons called "mental patients" the same rights (and duties) as are accorded all adults *qua* citizens or persons. (p. 19)

The National Association of Psychiatric Survivors (NAPS), founded in 1985 as the National Alliance of Mental Patients, promotes the same ideals Szasz espouses. The first item in its *Goals and Philosophy Statement* reads:

To promote the human and civil rights of people in and out of psychiatric treatment situations, with special attention to their absolute right to freedom of choice. To work towards the end of involuntary psychiatric intervention, including civil commitment and forced procedures such as electroshock, psychosurgery, forced drugging, restraint and seclusion, holding that such intervention against one's will is not a form of treatment, but a violation of liberty and the right to control one's own body and mind. We emphasize freedom of choice for people wanting to receive psychiatric services through true informed consent to treatment which includes the right to refuse any unwanted treatments. We will also work to assure the rights of all people who have been psychiatrically labeled including but not limited to people in halfway houses, day treatment, residential facilities, vocational rehabilitation, nursing homes, psycho-social rehabilitation clubs as well as psychiatric institutions. (NAPS, no date, p. 1)

This is the essence of "mental patients'" liberation. NAPS was formed specifically to counter the trend toward reformist "consumerism," which developed as the psychiatric establishment began to fund ex-patient self-help. Ironically, the same developments which led to the movement's growth and to the operation of increasing numbers of ex-patient-run alternative programs, also weakened the radical voices within the movement and promoted the

views of far more cooperative "consumers." The very term "consumer" implies an equality of power which simply does not exist; mental health "consumers" are still subject to involuntary commitment and treatment, and the defining of their experience by others.

It is not surprising that once the Community Support Program at NIMH began funding "consumer" conferences, the International Conference on Human Rights and Psychiatric Oppression disbanded. The first CSP-funded conference, "Alternatives '85," was held in Baltimore in June, 1985; the last International Conference in Burlington, Vermont, in August of that year. The dissolution was aided by a group of "consumers" who may have seen the liberation perspective as a threat. At the same time, some extreme radicals opposed any form of organization as oppressive, believing that a totally decentralized and unstructured movement could accomplish its goals.

Madness Network News disintegrated the next year. Its all-volunteer staff became exhausted by the effort of putting out the newspaper with no funds but member subscriptions, and they were succeeded by a very small group of extreme radicals who published only one issue — critical of anyone attempting to develop organizational structure or sources of funding for movement activities. The paper then ceased publication, leaving a gap in movement communication that went unfilled for several years. Although *Dendron*, a newsletter published by the Clearinghouse on Human Rights and Psychiatry in Eugene, Oregon, began publishing shortly thereafter, only recently has it become as visible within the movement as had been *Madness Network News*.

Where the Movement Stands Now

At present, many groups exist that claim to speak "for" patients, that is, to be patients' advocates. Even the American Psychiatric Association claims this role, as does the National Alliance for the Mentally Ill (NAMI), a group primarily composed of relatives of patients, which enthusiastically embraces the medical model and promotes the expansion of involuntary commitment and the lifetime control of people labeled "mentally ill." However, a basic liberation principle is that people *must* speak for themselves.

Former patients recognize numerous currents of opinion within their community (which, after all, numbers in the millions). There are groups whose members promote the illness metaphor (e.g., National Depressive and Manic-Depressive Association); groups whose members promote self-help in conjunction with treatment for illness (e.g., Recovery, Inc.); groups whose members see themselves as consumers (e.g., the National Mental Health Consumers' Association); and groups whose members see themselves as liberationists (e.g., National Association of Psychiatric Survivors). However, it is safe to say that by far the largest number of patients and ex-patients are those who identify

with *none* of these organizations — indeed most patients and ex-patients have probably never even heard of these groups.

The movement continues to face formidable obstacles. The psychiatric/medical model of “mental illness” is widely accepted by the general public. Indeed, new psychiatric “illnesses” are being “discovered” all the time, and psychiatry now claims that social deviants — from rapists to repetitive gamblers — are suffering from a variety of newly defined “mental illnesses.” Psychiatry is entrenched, as well, in the courts, the prisons, the schools, and all major institutions of society.

At the same time, there are many hopeful signs for the movement. The ex-patients' movement is developing alliances with the physically disabled, with the poor, and with ex-patients in other countries. Physically disabled people have organized their own self-help programs, using the model of independent living. According to the principles of independent living, any person — no matter how physically disabled he or she may be — can live independently if provided with the proper supports. Such supports must be individualized — a person may need special equipment, personal care attendants, modified transportation vehicles, and so forth. The particular mix of supports is determined by the individual, in consultation with an independent living specialist (who is also a physically disabled person). As the disability rights movement has grown, it has become a powerful force for legal change as well. For more than ten years, this movement has lobbied in favor of the Americans with Disabilities Act, the so-called civil rights bill for the disabled. The bill was signed into law on July 26, 1990. Although the ex-patients' movement entered that struggle late, the final version of the Act does include persons with “psychiatric disabilities” under its protections.

Linkages of the ex-patients' movement with the impoverished include efforts at affordable housing, campaigns for universal medical insurance, and involvement in the Rainbow Coalition. It has proved extremely useful for ex-patient activists to become involved in these activities — not only do ex-patients require the services being advocated but demystification in the eyes of one's allies can serve an invaluable purpose. When labeled as “mentally ill” — a nameless, faceless person — the “mental patient” may be seen as the enemy; as a co-worker and a colleague, facing the same problems and struggling for the same solutions, the ex-patient becomes an individual: knowable and understandable.

The growing internationalization of the ex-patients' movement is another sign of the movement's growth and strength. As groups exchange newsletters, and attend meetings and conferences, a shared ideology is developing. Although the lack of a solidifying terminology continues to be troubling, such variety does not necessarily indicate wide variations in viewpoints and activities. Whether group members call themselves clients, consumers, ex-

patients, users, or psychiatric survivors, groups throughout the world are united by the goals of self-determination and full citizenship rights for their members.

It is true that the vast majority of former patients remain unorganized, but this challenge is being met. As groups become more visible, they recruit more members. This occurs because ex-patient groups speak to a truth of the patienthood experience: that people's anger and frustration are real and valid, and that only by speaking out can individuals who have been harmed by the entrenched power of psychiatry mount a challenge against it.

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