

Planning a Community-Based Mental Health System

Perspective of Service Recipients

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ABSTRACT: *Two former patients, long-term activists in the self-help/advocacy movement, combine to provide a consumer perspective on planning mental health systems. Separately, each author notes current system problems, the need for new services—including self-help—and the opportunities provided by Pub.L. 99-660 for meaningful change, based as it is on the fundamental principle of involving the recipients of services in any planning effort.*

Judi Chamberlin

It is part of the conventional wisdom in this country that the mental health system is in trouble. For many years, people pointed to state hospitals—large, impersonal, underfunded, neglectful of the basic human rights of their inmates—as the main problem. More recently, it has become fashionable to blame deinstitutionalization (the process by which the state hospital population has been reduced to a fraction of those who were incarcerated a few decades ago) for all the faults of the mental health system. As with most things, the truth is far more complex.

Criticism of the mental health system comes from many directions and focuses on many different aspects. The media, which plays a large role in shaping public attitudes, tends to highlight stories of escaped or discharged patients who commit notorious acts of violence, despite the fact that “the mentally ill” as a group are no more violent (and probably are less violent) than the population at large. The public, therefore, tends to link mental illness with violence and tends to believe that people labeled *mentally ill* need to be incarcerated for society’s protection. Meanwhile, most of the mental health disciplines have concluded that long-term incarceration is part of the problem, and not the solution, and that mental health services can best be delivered in community-based programs, which have proliferated in recent years.

Average citizens seldom consider mental health issues at all, unless they directly affect their own lives. Therefore, public debate on mental health tends to be framed in a highly simplistic, media-influenced manner (“Ex-mental patient kills two”; “Homeless mental patients clog downtown”). Meanwhile, almost unseen by the media and by the major decision makers in mental health policy, such

as psychiatrists and government bureaucrats, a new group has begun debating these issues and devising solutions and programs that challenge the conventional wisdom.

Former mental patients have been organizing in the United States since the early 1970s. Small, locally based, and virtually unfunded, these groups have become increasingly vocal and active. Often highly critical of the existing mental health system, they have proposed major changes in the way the system is run and on where its focus should be.

The prime motivation of people who join ex-patient organizations is a desire to counteract the feelings of powerlessness they experienced as patients in the system. Traditionally, mental patients have been viewed as incapable of defining their own needs, and others (family members, mental health professionals, the state) have controlled their lives and made decisions on their behalf. These interventions, always justified as being in the best interest of the patient, have been responsible for much human suffering, including long-term incarceration, forced drugging, massive use of electroshock and lobotomy, and the denial of basic legal rights and human dignity. It is not surprising that patients themselves have begun to define themselves as an oppressed group, to call for their own liberation, and to redefine problems and solutions.

Among the many goals of the ex-patients’ movement (which includes diverse local, regional, and national organizations) is to play a part in devising mental health policy, rather than to be merely the passive objects of policies designed by others. Public Law (Pub.L.) 99-660, which requires states to develop plans for implementing a community-based system of mental health care and requires the participation of diverse constituencies in the planning process, is one possible vehicle for the ex-patients’ movement to promote its visions of how help should (and should not) be made available to people who are troubled or dysfunctional.

It is not surprising that the various constituencies have highly differing visions of what the mental health system should do and how it should be organized: Like the blind men and the elephant, each group sees the problem from its own perspective and each tends to think its view is the whole picture. Thus, psychiatrists call for more psychiatrists and psychiatric control of the system.

Other mental health practitioners (psychologists, social workers, nurses, occupational therapists and so forth) call for more money and prestige for their respective disciplines. Legislators want to see that costs are kept low and the public is protected. State hospital administrators believe state hospitals are essential. Community providers think that too much money goes to the state hospitals and not enough to their programs. Family members focus on the urgent needs of their relatives.

Now here comes a new group—patients and ex-patients, the actual recipients of services—presenting a whole new viewpoint. If Pub.L. 99-660 is implemented as intended, it will provide an opportunity for these diverse groups to interact, exchange ideas, and, perhaps, to begin to understand their often dramatically different viewpoints.

In addition to providing for planning by the diverse mental health constituencies, Pub.L. 99-660 requires that state mental health systems be community based. This is highly significant, because although state hospitals may possibly still play a part in such a system, they will no longer be its focus, and it is quite possible that states may devise systems that eliminate them entirely. Vermont is currently implementing a carefully crafted plan (which included the participation of diverse constituencies, including, very prominently, ex-patients) for virtually closing down its state hospital, without abandoning people to the streets or to shelters (Carling, Miller, Daniels, & Randolph, 1987). It is exciting to look forward to a variety of approaches in different states to making mental health programs truly serve the needs of those who receive services, by including their representatives in the processes of change.

I have worked in the ex-patients' movement for more than 15 years, and have seen the movement grow from a few scattered local groups to a profusion of organizations and projects. Ex-patient self-help groups, which I first wrote about in 1978, are now a reality in dozens of locations around the country (Chamberlin, 1978; Zinman, Harp, & Budd, 1985). Self-help will surely be included as a component of many state plans: One of the goals of the ex-patients' movement is to ensure that each state includes provisions for adequate funding of self-help programs and whatever technical assistance is necessary to aid groups to develop such programs.

It has become fashionable in recent years to refer to recipients of mental health services as *consumers*, a term that I and many other ex-patients find objectionable because it implies that we have choices and power. In fact, we are seldom consulted about whether we want services at all or what form such services should take, or asked whether we are satisfied with the services we have received. Whereas corporations spend millions of dollars to try to find out what their customers or potential customers want,

mental health systems often work with a captive population that cannot take its business elsewhere. The term *consumer* in itself is not empowering; in fact, it is often used to obscure the true power relationship in which the service recipient has no leverage at all.

Perhaps the planning process required by Pub.L. 99-660 will help us to become true consumers, who "shop" for services we want and reject those that do not meet our self-defined needs. Then we will see real, fundamental change—not just new names for old institutions and programs, but a true revolution challenging the very basis of paternalism and control.

Joseph A. Rogers

I know, from personal experience, what a mental health system should *not* be. I have sat, strapped in restraints, in an isolation room in a community hospital for three days, while people came and went, not to talk to me but to drug me into a stupor. I know that's not the way to help people.

I also know that state hospitals are not the way. Almost all of the state hospitals that I've had experience with are huge, antiquated, wasteful places in which precious little help can be found (Rogers & Centifanti, 1988). They seem to exist mostly to provide jobs for staff.

So how can you improve a system such as this? How do you build a mental health system that comes as close to the ideal as possible? Very simply, you start by considering clients' needs and how those needs can be met. Second, you involve clients as equal partners in the system—in planning, implementing, and providing services.

Building a System Based on the Needs of the Individuals It Serves

First, what do we need? We need what everyone else needs: a place to live, a job, and friends.

Work is vital to people's sense of self-worth, not to mention their ability to be independent. Although adequate public benefits should be available for people who need them, it is damaging to a person's self-esteem to have to depend upon them. Unfortunately, many people with psychiatric histories don't think there is any other option, because their involvement in the mental health system has drained whatever self-esteem they had. A lot of people are scared: Finding a job and risking losing it and not being able to get back on Social Security can feel like tightrope walking without a net. And the public benefits system, with all its disincentives to work, needs to be overhauled with an eye to helping people get on their feet so they won't need public benefits.

The recent passage of the Americans with Disabilities Act (Pub. L. 101-336) not only establishes work as an obviously vital part of rehabilitation, but mandates that all people with disabilities, including mental disabilities, have a right to work.

An ideal mental health system would include job training. I'm talking about a program that would help people achieve their highest potential, not just a menial job. Helping people become independent through work

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should be a key element in all rehabilitation programs. Work need not be the traditional nine-to-five job—it can also be volunteer work or an education program—but people need to do *something*.

A lot of what passes for job training (e.g., vocational screenings and “sheltered workshop” programs) is actually disabling. It makes people more dependent on the system because it gives people the impression that the world of work is a “big deal,” some kind of secret society that they can never break into. In some cases, if we just gave people the want ads and said, “Here are some subway tokens; I know you can do it, good luck,” people would go out and get jobs. They may get fired from the first job, or the second or the third. Or they may not like a job and quit. But who has not had these experiences? They’re part of life.

Jobs also provide social supports—a network of people you can socialize with, at least casually around the water cooler once or twice a day. People need contact with other people. If you’re living on Social Security, there’s almost no money left for any kind of luxuries, including social activities. Even if you’re working, it’s usually at a menial job with a low salary. People end up sitting in a room by themselves watching TV, if they’re lucky enough to have a room. The poverty, anxiety, and loneliness contribute to a huge sense of social isolation. A good community-based system would address that need.

Self-help programs are an indispensable part of any community-based mental health system and should be a high priority to receive funding. Such user-run programs as drop-in centers and peer case management provide people with a feeling that they can give as well as receive help, which builds self-esteem. At drop-in centers people can find friends and a sense of belonging, maybe for the first time in their lives. They also meet role models—other consumers who are making it in the community. Self-help groups and other user-run programs answer the question, Is there life after psychiatric hospitalization? with a resounding Yes! (Artison-Koenning & S. Rogers, 1988; Centifanti, 1988a, 1988b; Lovejoy, 1988; MEEK, 1988; National Mental Health Consumer Self-Help Clearinghouse, 1988a, 1988b; J. A. Rogers, 1988a; J. A. Rogers & Centifanti, 1988; S. Rogers, 1988).

Housing is another great need. Being on Social Security brands you as an undesirable tenant in the eyes of many landlords. The housing that the mental health system offers is usually short-term, congregate living.

Although congregate living may actually alleviate some of the isolation people feel by providing an instant support network, it is important that it not be so transitional in nature (e.g., the “two years and out” policy in Pennsylvania). With short-term housing, just as you are beginning to stabilize your life you are under pressure to leave the residence.

If the system took a portion of the money spent on residential programs and put it into rent subsidies, it would help people grow to independence. Apartments that are almost impossible to rent on a few dollars, es-

pecially on Social Security, are attainable with some help, such as money toward the first and last months’ rent and maybe some help with furnishings, supplies, and utilities. That may be all some people need. Others may need a continued rent subsidy, such as is available under Section 8 housing. But there must some kind of subsidization so that people can live independently and with dignity.

Consumer Advocacy

Self-help programs empower people so that they can participate not only as clients of the mental health system but as vocal advocates for whatever is positive in the system and, more important, for systems reform. Empowered consumers can testify to the importance of funding mental health programs. Self-help programs are also a formalized way of getting people who have overcome their problems to continue to be involved and provide role models for those coming after them.

Peer support may be best, but other volunteers of the community, such as members of church groups, can also be caring friends and excellent role models. An ideal system would recruit volunteers from the community.

In self-help groups people can organize for change not only in the system but in the community, against the stigma and discrimination that plague people with psychiatric histories.

Mandate for Consumer Involvement in System Planning

I am extremely excited about the possibilities that the Mental Health Planning Act (Pub.L. 99-660) presents. This is one of the first pieces of national legislation to mandate consumer involvement. I believe that any planning process that fails to significantly involve consumers from the ground up is not living up to this mandate. By significant involvement, I mean a cross-section of individuals, not just one or two token consumers; I mean people representing geographic, racial, political, and experiential diversity.

Part of the organizing that the National Mental Health Consumer Self-Help Clearinghouse has done is to consider how to have an impact on services. We are organizing consumers who are involved in the mental health system. They are interested in what the services look like, how to fund them, and how to improve them. This is taking place all around the country. In fact, the National Mental Health Consumer Self-Help Clearinghouse has done consulting in some 30 states and Puerto Rico.

If any plan for systems change is going to be realistic and work, it must involve us, because as we become more organized we are demanding systems change (J. A. Rogers, 1988b). In essence, unless planning groups and councils are made up of at least one-third mental health consumers, they are failing to live up to what we consider the mandate of the plan.

Consumer involvement is an essential part of putting together a good plan. Who except the actual users of services can give you the straight dope on the impact of services? Until you’ve actually lived in an inpatient pro-

gram, you really can't get a sense of what the program does for you or to you. Until you've been dependent on a case manager for basic essentials, such as income, food stamps, and so on, you don't really have a sense of how vital those services can be and how great the frustrations that you may have to face can be in dealing with the bureaucracy that doles them out.

We have found that individuals in our movement have a commitment (no pun intended) to seeing changes made that often surpasses the commitment of people who never expect to have to live with the results of their planning.

Beyond experience and commitment, consumers also generally have untapped amounts of time and resources, in many cases. Unfortunately, many consumers are unemployed. This is a resource that should be tapped, both on a volunteer basis and, I hope, on a paid basis.

Financing Mental Health Services

The final question is the bottom line: How should mental health services be paid for? I suggest that the most workable system is one of single-stream funding, which gives communities both the incentive and the funding to come up with a decent community mental health system.

Under single-stream funding, local governments would be responsible for determining the individual needs of persons with mental illnesses and for developing programs to meet those needs. The system allows funds to follow the patient, and places fiscal incentives on the least restrictive treatment consistent with excellent care.

Unfortunately, in many states the lion's share of the mental health budget is fed into the gaping maw of the state hospital system. This makes the local government a kind of toothless tiger, with neither the incentive to develop cost-effective community-based alternatives to costly inpatient treatment, nor the funds to do so (J. A. Rogers & Centifanti, 1988).

Single-stream funding is an eminently reasonable system, under which local authorities would be responsible for treatment decisions and control the funds to implement those decisions. They would thus have an incentive to implement programs to intervene before hospitalization becomes necessary, to develop more effective community alternatives to inpatient hospitalization, and to limit the length of any hospitalization to the necessary minimum.

How would this work? For example, local authorities would contract for the use of state hospital beds for their committed patients on the basis of where they are treated or the specific type of service they receive. The fewer patients they sent to state hospitals, the more money they would have for community programs. Meanwhile, those overusing their share of state hospital beds would pay for that privilege. What do you want to bet that fewer folks would be sent to state hospitals?

Under the ideal mental health system, there would be no need for involuntary commitment. The concept rests on the false notion that committing more people to

mental hospitals will increase public security. In fact, for each person thus expensively committed, several more people with serious mental illness will remain in the community with no hope of receiving any help at all.

Take the state of Washington, which in 1979 changed its laws to make it easier to lock people up. According to University of Washington professor Mary L. Durham, who did a five-year study of the effects

Broadening involuntary commitment laws did *not* protect the community from dangerous people, it did *not* solve problems of homelessness, it *wasted* precious resources and it created a dependency on the involuntary commitment system that brought people back again and again to that hospital system. . . . Washington State now represents what I would consider the worst of both worlds. (Joint State Government Commission Task Force, 1987)

We don't need more people committed to programs; we need more programs committed to people. Ultimately, an ideal mental health system would concentrate on the belief that success is possible—that people can overcome their problems and live independent, productive lives in the community.

REFERENCES

- Artison-Koenning, R., & Rogers, S. (1988). *How to develop a consumer-run newsletter*. Philadelphia, PA: National Mental Health Consumer Self-Help Clearinghouse.
- Carling, P. J., Miller, S., Daniels, L., & Randolph, F. (1987). Operating a state mental health system without a state hospital: The Vermont feasibility study. *Hospital and Community Psychiatry*, 38, 617-623.
- Centifanti, J. B. (1988a). *Systems Advocacy*. Philadelphia, PA: National Mental Health Consumer Self-Help Clearinghouse.
- Centifanti, J. B. (1988b). *Who's who in the mental health system*. Philadelphia, PA: National Mental Health Consumer Self-Help Clearinghouse.
- Chamberlin, J. (1978). *On our own: Patient controlled alternatives to the mental health system*. New York: Hawthorn Books.
- Joint State Government Commission Task Force on Mental Health Laws. (1987). *Transcript of public hearing: Vol. 1. Wednesday, January 28, 1987*. Harrisburg, PA: Author.
- Lovejoy, M. (1988). *Organizing and operating a speakers' bureau*. Philadelphia, PA: National Mental Health Consumer Self-Help Clearinghouse.
- Meek, C. M. (1988). *Consumer-run drop-in centers*. Philadelphia, PA: National Mental Health Consumer Self-Help Clearinghouse.
- National Mental Health Consumer Self-Help Clearinghouse. (1988a). *Jobs, jobs, jobs!* Philadelphia, PA: Author.
- National Mental Health Consumer Self-Help Clearinghouse. (1988b). *Making our voices heard: Consumer representation on decision-making committees: "No longer will we be silent."* Philadelphia, PA: Author.
- Rogers, J. A. (1988a). *How to start a self help/advocacy group*. Philadelphia, PA: National Mental Health Consumer Self-Help Clearinghouse.
- Rogers, J. A. (1988b). We have to begin to create a movement that is basically a civil rights movement. *Your Choice*, 1(3), 2, 5, 7, 15.
- Rogers, J. A., & Centifanti, J. B. (1988). Madness, myths, and reality: Response to Roberta Rose. *Schizophrenia Bulletin*, 14, 7-15.
- Rogers, S. (1988). *Fighting stigma*. Philadelphia, PA: National Mental Health Consumer Self-Help Clearinghouse.
- Zinman, S., Harp, H. T., & Budd, S. (Eds.). (1985). *Reaching across: Mental health clients helping each other*. Sacramento: California Network of Mental Health Clients.