

Reinventing Mental Health Care

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Famously—and for the flimsiest of reasons, ranging from a governmental desire to save money to the once-fashionable belief that mental illness is only a different but perfectly valid form of consciousness—the nation largely dismantled its mental health care system over the last 40 years. Less well known, though, is that the outlines of a reasonable new mental health system have quietly begun to take shape. So far, it is a tentative, piecemeal development; and federal policy, instead of helping it cohere into a rational, comprehensive whole, is stymieing and retarding it at every point. For that reason, it seems important to spell out just what the emerging new U.S. mental health care system looks like—and how policymakers can help ensure that what finally takes form will be as rational, humane, and effective as we can make it.

The first key element of the new system, as *City Journal* readers well know, is a legal instrument to require people with serious mental illnesses to take the medication that in most cases will control their symptoms and allow them to live better lives (see "[We've Tried Mandatory Treatment—and It Works](#)," Summer 1999). Half of all individuals with diagnoses of schizophrenia and manic-depressive illness, the two diseases that constitute the vast majority of severe mental illness, have limited awareness of their condition, because it has affected that part of the brain used for self-awareness. Such individuals do not voluntarily seek treatment or accept medication, since they think that nothing is wrong with them. But even among some of the mentally ill who *are* aware of their illness, the unpleasant side effects of psychotropic drugs—ranging from tremors or sedation to sexual dysfunction to substantial weight gain—can discourage them from taking their prescribed medicine.

On August 5, New York became the 41st state to pass a mandatory treatment law, requiring persons with these illnesses to take their medication or be hospitalized until they agree to do so. Mandatory treatment laws increase the medication compliance of mentally ill people threefold, reduce their hospital re-admissions from 80 percent to less than 50 percent, and cut down on violent episodes. No longer will patients have to do grievous harm to themselves or others before being medicated, and the 1,000 or so homicides committed each year by people with serious mental illnesses—cases like the murder of Kendra Webdale, pushed under a New York subway train by Andrew Goldstein—should begin to decline.

But mandatory treatment solves only part of the mental health care problem. Even when they take their medication, severely mentally ill individuals living in the community need help. They need coordinated outpatient services, since navigating the byzantine world of helping agencies is difficult enough for someone whose brain works normally; for someone with schizophrenia or manic-depressive illness, it is impossible. They need social and vocational assistance, too, since many of them suffer from isolation and loneliness and, because of their condition, haven't attained the educational and work experience that might help them become more independent. Finally, they need a specialized kind of housing, tied to medication maintenance and to other

coordinated support services. The idea that individuals with severe mental illnesses can live anywhere and just need subsidization of their housing costs is a myth that has led to many disasters.

At present, however, some 200,000 mentally ill people are homeless, and the only housing we provide for other mentally ill people is jail or prison. A July 1999 study by the Department of Justice reported that 16 percent of the inmates in state prisons and local jails—275,900 individuals—are mentally ill. The mentally ill inmates are also more likely to be in prison for a violent offense (53 percent) than are other inmates (46 percent). The Los Angeles County Jail, with 3,400 mentally ill prisoners, is de facto the largest psychiatric inpatient facility in the United States. New York's Rikers Island jail, with 2,800 mentally ill prisoners, is the second largest, and each prisoner costs taxpayers \$175 per day. In many counties throughout the nation, the local jails hold more mentally ill people than do the local psychiatric facilities. Released prisoners, rarely treated, too often alternate between homelessness and incarceration, like Gloria Rogers, a mentally ill Tennessee woman, jailed 114 times in the past four years.

Yet in almost every state, you can find good programs that provide housing and services to perhaps 1 or 2 percent of the people who need such care, and if we could replicate them on a national scale, we'd have a mental health system that works. For coordinated outpatient services, the most effective model is Assertive Community Treatment (ACT) teams, also known as continuous treatment teams. These teams, usually made up of eight to ten professionals and paraprofessionals—including a psychiatrist and psychiatric nurses—and linked to a hospital or a community mental health center, take responsibility for 100 to 120 severely mentally ill individuals for up to 24 hours a day, seven days a week, as needed.

Based on a model first developed in Wisconsin in the early 1970s, ACT teams bring treatment to the patient, rather than wait for the patient to seek treatment. ACT teams aggressively search for the untreated mentally ill in homeless shelters and jails to get them cared for, to determine their appropriate medicine, and to ensure that they take it. ACT teams also help severely mentally ill individuals who've been released from hospital ease their way back into society. A team member will visit, often daily, a newly released patient wherever he lives—whether in a group home or in his own apartment—to check up on his medication compliance. In addition, ACT teams offer "practical on-site support in coping with life's day-to-day demands," as one of the model's architects, psychiatrist William Knoedler, puts it. An ACT team worker will assist in the routine household chores, from buying groceries to paying bills, that are often forbidding to the severely mentally ill when they first return to the outside world.

The ACT model has proven both clinically effective and affordable. Michigan has had the most experience with ACT teams, with more than 120 now up and running, and the state has reduced re-hospitalization by 90 percent. Randomized trials in Australia, England, and the U.S. have demonstrated a more modest, but still significant, 50 percent reduction in re-hospitalization for patients treated with this model. The mentally ill and their families express satisfaction with it. The total cost of care per patient for ACT teams is approximately \$50 a day—less than the cumulative costs of re-hospitalization, several studies have shown.

Despite this successful history, however, ACT remains frustratingly limited in its reach. So far, only five states other than Michigan have ACT teams available statewide, though 19 states and the District of Columbia now have ACT demonstration programs in place.

The most effective means for providing people with severe mental illnesses the social and vocational supports they need is the clubhouse model, patterned after New York City's Fountain House, opened with private funds in 1948 and still going strong, with a \$14 million annual budget. (As with most clubhouses, today its funding comes primarily from government sources.) Clubhouses are community facilities, usually open 365 days a year, in which mentally ill individuals—called "members"—get together in a non-threatening, stigma-free atmosphere. Clubhouse staff dress no differently from members, don't give out medicine, and don't offer

therapy, but do stress to members the importance of taking medication.

Clubhouses provide the severely mentally ill with community and work. A bustle of social activity greets a visitor to Fountain House's spotlessly clean headquarters in midtown Manhattan: mentally ill individuals are learning about their illnesses, receiving tutoring to get a high-school equivalency diploma or to get up to speed for community college, talking in the sunlit rooftop café, even filming an educational program to air on the clubhouse's in-house TV station. Together with staff, Fountain House's members (1,300 on the active roster) make the clubhouse run by answering phones, guiding tours, and preparing and serving lunch for members, staff, and visitors every day. Though several severely mentally ill people sit quietly, staring blankly, and a few others appear completely out of sorts, the general impression is one of hope and striving—and a certain *esprit de corps*.

Most clubhouses, Fountain House included, stress the importance of work as a reintegrative force in the life of the mentally ill. One of the country's best is the 120-member Green Door in Washington, D.C., and work is central to its mission—"real work, not make-work," emphasizes executive director Judith Johnson. The Green Door, like Fountain House and many other clubhouses, offers a three-stage work program for its members that boosts their confidence, teaches skills and good work habits, and increases their independence.

Green Door's program begins with supported work on clubhouse premises. It might just be sweeping the floor, but the key, Johnson explains, is to build confidence—to make members aware that they *can* work, and that they aren't simply passive recipients of others' care. A member who feels ready will then try working outside the Green Door, in a carefully controlled setting. The clubhouse has arrangements with several companies, including MCI and Marriott, to provide 25 or so six-month jobs for members—usually entry-level duties cleaning up, helping in the kitchen, or sorting mail, since most of the severely mentally ill don't have college degrees or much work experience, and some are too ill to do anything more ambitious. These transitional positions are popular with the employers, because if a member doesn't show up for work or doesn't do the job adequately, Green Door staff will fill in. Fifty percent of the members fail in their first transitional job, but only 25 percent fail the next time out, and almost nobody fails the third time.

After members complete a few of these six-month transitional jobs successfully, a real job follows. The clubhouse helps its members write résumés, and staff members comb through newspaper classifieds to find them positions. Once employed, members can get promoted or lose their jobs, like anyone else. The Green Door currently has 50 members in permanent positions—again, mostly at the entry level. But college-educated members have gotten much higher-level jobs. One works in a stockbroker's office, another in a university financial-aid department; and in a striking success story, Alese Witherall, a schoolteacher before falling ill with schizophrenia, now works for the Federal Reserve, making \$35,000 a year.

True, director Johnson acknowledges, not every mentally ill person can go back to work. Some members are so impaired that success for them is simply to get out of bed in the morning, stay out of the hospital by taking medication, and make it to the clubhouse. Others, who may have spent most of their adult lives in mental institutions, view themselves as retired. But nearly half of all people with severe mental illness are capable of working at least part-time, thanks to programs like the Green Door's—a remarkable improvement over the 5 percent of the seriously mentally ill employed nationally.

Like ACT, clubhouses have proven both effective and affordable. In addition to the high employment rate of its members, the Green Door boasts an annual re-hospitalization rate for members of just 12 percent. The total cost of running the Green Door is around \$6,000 yearly per member. Even if you add \$15,000 for housing to the Green Door's \$6,000 cost, the total is cheaper than jail, at some \$60,000, or persistent re-hospitalization. Other clubhouses have achieved similar results. Yet, like ACT again, clubhouses aren't nearly as widely available as they

should be, with fewer than 150 operating in the United States to date.

The severely mentally ill also need a special kind of housing to go with coordinated outpatient services and social and vocational assistance. Some effective housing programs for them already exist, the best featuring an array of options, so that a mentally ill person can get varying levels of supervision depending on his clinical state. Some severely mentally ill individuals—often those new to treatment, homeless and unmedicated a short time before—require 24-hour, on-site supervision until their condition stabilizes, while the least ill, suitably medicated, can live more or less on their own. Yet others require something in between—supported living in a group home, say, or living in an apartment with weekly visits from a mental health worker. And since many of the severely mentally ill move through cycles of relapse and remission, they require different kinds of housing at different times.

Clubhouses often have excellent housing programs—in Fountain House's case, quite a big one, accommodating nearly 500 residents in a variety of housing throughout New York City, costing a little over \$40 a day per person. One of the nation's best housing programs for the severely mentally ill is in Chicago, run by Thresholds, a big nonprofit organization that got its start as a clubhouse before branching out to include therapy in its rehabilitative services. Thresholds accommodates 700 severely mentally ill individuals in a host of group homes, apartment houses, individual apartments, and single-room-occupancy hotels located throughout the Windy City. Supervision ranges from the intensive to the mostly independent. Thresholds spends \$7 million of its \$34 million yearly budget on its housing program (about \$27 per individual per day), with the additional funds flooding into an array of services, including educational and therapeutic workshops.

For the mentally ill homeless, religious groups have been especially effective housing providers. The St. Francis Residences in New York City are exemplary. Three renovated hotels, they have 280 clean and brightly painted rooms for severely mentally ill individuals, most of them previously homeless, and the friars arrange for the tenants to have exercise, social activities, and two meals a day. They also link tenants up to psychiatric services. As one older resident enthused about the friars to a reporter, "They're concerned about us, concerned about our health. You have the feeling you're not alone." Franciscan frugality provides these formerly homeless mentally ill tenants a room and hot meals for just \$15 a day.

With proper medication, and with housing and services like these, the vast majority of those with severe mental illnesses can live in the community, though often not fully integrated into it. Even so, a humane mental health care system will still need some long-term inpatient beds for acutely ill individuals and for that small number of patients who do not respond to currently available medicines.

The 200-bed New Hampshire State Hospital is probably the nation's most admirable example of such an institution. Well-managed and staffed by quality mental health professionals whom the Dartmouth Medical Center recruits and supervises on state contract, the hospital has minimal staff turnover and thus good continuity of care. The hospital works hard to make life there more pleasant for patients; it shows a nightly movie, with popcorn, for example, and tries to create a homey atmosphere. It also offers a variety of treatment alternatives for inpatients, depending on the severity of their illness. The average length of stay for those in the temporary admission unit is eight days, while those in the continuing care unit remain for six weeks to six months. Only a few patients need to remain for a year or more, usually because complicated brain damage makes community care unrealistic.

New Hampshire boasts the best public inpatient facility and some of the best outpatient facilities in the nation, thanks to intelligent leadership in the state mental health system and the state government for more than a decade. As the state's 2,200-bed mental hospital system gradually discharged patients, officials wisely reinvested the money they were saving into the ACT teams and other outpatient services that the first-rate Mental Health Center of Greater Manchester

employs. New Hampshire also benefits from a significant research program linked to its Dartmouth contract, investigating what services work and how to do things better.

If such superb models exist from coast to coast, why aren't they proliferating rapidly and joining up to form a coherent national system? The simple answer: Washington. The federal government, which in 1962 contributed just 2 percent of the total funds in the mental illness system, today contributes two-thirds. It dominates the system through Medicaid and Medicare, the two huge federal paws that reach out and affect almost every decision regarding treatment at the state and local levels, and through a confusing swarm of other federal programs, the biggest of which are the SSI and SSDI disability insurance programs. Combined, federal programs spend more than \$40 billion a year on mental disorders, with Medicaid paying out more than a quarter of the total—and the amount is steadily growing. This massive shift of costs from the state to the federal level has been the biggest cause of the crisis of the mental health system.

The reason is a classic story of unintended consequences. When, during the 1960s, a well-intentioned federal government first launched Medicaid and other programs that offered benefits to the mentally ill, it excluded payments to state psychiatric hospitals and other state institutions for the treatment of mental diseases. The feds originally had intended only to extend a helping hand for those mentally ill individuals whom state hospitals discharged into the community, not to take on most of the burden of the mental illness treatment system, which, after all, had been a state responsibility since the early nineteenth century.

Tragically, the feds assumed that their financial assistance would be of short duration, since the prevalent view—noisily trumpeted by civil libertarians and the psychiatric establishment—was that mental illness was partly the product of psychiatric institutionalization itself. Once released from these oppressive institutions and given modest financial aid, the fashionable thinking ran, most mentally ill individuals could function on their own, perhaps occasionally dropping by the 800 or so new, federally created "community mental health centers" to receive free outpatient treatment. (These centers, with a 20-year federal mandate but little oversight, degenerated almost instantly into founts of social activism, ignoring the needs of the mentally ill. Today, their mandate ended and their funding dried up, most of them have closed their doors or have become counseling centers.)

As the new federal programs kicked in, though, something quite different happened: state governments quickly discovered that they had a huge fiscal incentive to push patients out of state mental health institutions, and little incentive to care what happened afterward. For the seriously mentally ill, the consequences were a disaster. State psychiatric hospitals, under state government pressure to transfer costs to the federal level, inappropriately discharged scores of patients. Many of these psychiatrically disabled individuals, instead of flourishing on their own as the fashionable psychiatric and libertarian orthodoxy promised they would, fell between the cracks of the treatment system and wound up homeless or in jail, where local government bore the costs. Others, on paper deinstitutionalized, found themselves "transinstitutionalized"—shunted into nursing homes or kindred institutions, where federal funds did pick up the tab, but where little or no inspection took place and where staff wasn't trained to treat mental illness. And because federal funds were available for psychiatric care in general hospitals but not in state psychiatric hospitals, most inpatient care for the mentally ill now took place on general hospitals' psychiatric wards. Unfortunately, these wards too often were inappropriately staffed and offered little follow-up care. Reluctant to treat severe cases of mental illness, the general hospitals were simply turning away patients suffering from schizophrenia or other severe conditions.

Beginning in the sixties, then, the big question driving the emerging mental health system was not "what do patients need?" but "what will federal programs pay for?" But even as its role in the mental illness system grew exponentially, the federal government proved grossly incompetent in filling the system's widening cracks. Federal bureaucrats at the Health Care Finance Administration (HCFA) headquarters in Baltimore ultimately decided which treatment services were eligible for federal reimbursement and which weren't, and in which states. Many of these

bureaucrats had never seen an individual with a severe mental illness and had no knowledge of local resources and conditions, which varied widely from Stark County, North Dakota, to Los Angeles County, California. How could they make informed decisions on what services to fund, especially since no authoritative mechanism was in place that might have allowed them to determine which programs actually helped the mentally ill and which were the most cost-effective? The result was a hodgepodge of confusing and conflicting regulations that left the mentally ill in the lurch.

Ed Francell, a former mental health administrator in Georgia, vividly describes how bizarre the regulations had become—and how counterproductive to effective treatment. "While I was an administrator," he recalls, "we actually talked very little about clinical services and almost entirely about how we could 'game' the system to get as much Medicaid revenue as possible." One absurd but typical example: since Medicaid allows reimbursement for emergency crisis services in Georgia only when they are provided to psychotic individuals outside their homes, Francell recounts, "we actually instructed clinicians to try to coax the [patient] outside the house into the front yard to be able to bill the service." Medicare regulations are equally absurd, requiring a psychiatric nurse in Washington state, for example, to maintain two offices three miles apart on either side of the county line to maximize reimbursements.

The increasingly bureaucratic and federally dominated mental illness treatment system has snuffed out promising new initiatives and hampered proven innovations from expanding. As early as the 1960s, a pilot program in Louisville, seeded modestly with state money, demonstrated that public health nurses making daily home visits to acutely psychotic patients prevented many hospitalizations; though it was cost-effective, this proto-ACT program didn't get off the ground because it didn't qualify for Medicaid funding. Similarly, during the early 1970s, a pilot program in Denver demonstrated that using "crisis homes" to stabilize acutely mentally ill individuals instead of having them hospitalized was both clinically effective and cost-effective; it, too, died for lack of federal funds. Thanks to truly imaginative fund-raising—drawing on federal grants, state and local money, and private benefactors—a small number of ACT teams and clubhouses have been able to take root, but the extreme difficulty of accessing federal money, Medicaid above all, has sharply limited their growth.

The vast SSI and SSDI disability programs—together they paid out more than \$17 billion in 1997 to those suffering from mental disorders—have added to the federal damage to mental health services, in two ways. First, federal rules prevent mentally ill SSI and SSDI recipients from working more than a nominal number of hours without losing their disability benefits and, even worse, their Medicaid coverage, too—so that they can no longer afford the pricey medication that enables them to work in the first place. The fear of lost benefits—and thus, the fear of not being able to work at all—discourages many of the mentally ill from working more than part-time.

The second way these programs cause damage is that SSI and SSDI money comes to recipients in the form of monthly checks—approximately \$500 a month for SSI and \$700 a month for SSDI—with few restrictions on how recipients use the money. But while such a system makes sense when the recipient is rational, the mentally ill by definition aren't always in command of their faculties. Too often, these federal monies have simply subsidized self-destruction, particularly with the mentally ill homeless, who often spend their government checks on alcohol or drugs. As if these poor uses of government funds weren't bad enough, federal grants also fuel forums for counterproductive mental illness advocacy, like the Center for Mental Health Services and the Protection and Advocacy program. Both these institutions, completely under the influence of anti-treatment advocates, spend their time discouraging the mentally ill from seeking the treatment they need.

The proper reform of the federal role is simple, if ambitious: block-grant as much as is politically feasible of the more than \$40 billion in federal funds spent yearly on the mentally ill to the states and then hold the states responsible. Ideally, the federal government, which has done an abysmal job in the provision of human services, should get out of the mental illness treatment

business altogether, except for keeping statistics and monitoring quality of care. Instruments for the measurement of treatment outcomes are reasonably well developed but little used. Such instruments can include evaluations by patients themselves of their sense of well-being and assessments by mental health professionals of patients' conditions, taking into account, say, symptom reduction. They can include outcomes of programs, too, such as the proportion of their clients who work or who have been re-hospitalized. Finally, they can include broader community outcomes, such as the number of homeless mentally ill, the amount of police time spent on mental illness crisis calls, and the number of mentally ill people held in jail. (Federal inspectors could do surprise checks of jails to make sure that states were giving an accurate head count.) We could call such an approach measured care.

How would such a system work in practice, and how would the federal government be sure that states, counties, and cities were providing the needed services? Under measured care, the federal government would compare and publish treatment outcome data collected at the state and local levels. States would receive ratings based on their treatment outcomes; the feds, in allocating the block grants, would then reward those states doing the best job. States that, say, let homeless mentally ill individuals use government funds to drink themselves to death would receive poor ratings and lose potential funds. And since the number of mentally ill people in jails would be a negative measure, states would no longer be content to leave them there, shifting the cost of upkeep for the mentally ill downward to the localities that pay for the jails. The feds would also have to ensure that block-granted funds for psychiatric services went to serve the mentally ill, not to build sports arenas.

A non-political body—perhaps the National Academy of Medicine or something akin to the commission that monitored the quality of psychiatric care in England from 1845 to 1912—would make the final assessment of treatment outcome data. The federal government would have a huge stake in making sure that mental illness programs are effective, since it pays hugely to fund them.

Once the federal government devolves the mental health care funds to the states, the states in turn should transform the way they disperse the money. They should stop reimbursing specific services, whether or not anyone needs them or whether or not they lead to any useful outcomes. Instead, in the same way that they decide how to fund other social services providers, states would learn through trial and error what mix of innovative institutions is appropriate, where those institutions should be located, and which of them does the best job. They would re-allocate contracts based on their own outcome measures. Sensible advocacy groups like the Alliance for the Mentally Ill could play an important role in evaluating programs, as various state branches of the alliance have done already.

Second, experience strongly suggests that funding for mental illness services should go to the private, not-for-profit sector, which has a respectable history in providing services to the mentally ill. In government provision of services, civil-service regulations inhibit the flexibility necessary to meet the daily crises inherent in treating mentally ill people, though a few state programs, as in New Hampshire, have proven exceptions. And, so far, for-profit provision of mental illness services—at least under the present psychiatric care system, in which fewer services bring greater profits, and which doesn't take into account treatment outcomes—has proved a bad and scandal-ridden option.

What programs might the federal government feasibly transform into block grants without igniting a political firestorm? The mental illness entitlements of Medicaid and Medicare, which fund services but don't arrive as individualized checks in the mail, would be the best place to start. In fact, in 1995 Congress passed a bill block-granting all of Medicaid to the states, only to watch President Clinton veto it. But the ideal is clear enough: a dramatically scaled-back federal role, a sensible set of financial incentives, and measured treatment outcomes.

Die-hard believers in the civil-libertarian rhetoric of the 1960s—the American Civil Liberties

Union, say, and radical law groups such as the Bazelon Center of Mental Health Law in Washington, D.C.—will fight these developments bitterly, but theirs will be a rear-guard action, doomed to failure. The future of mental health care in the country is already beginning to take shape. Because so many of the needed changes are at the level of federal agencies, a bold new presidential administration will have a marvelous opportunity to accelerate its process, take credit for its successes, and improve vastly the lot of hundreds of thousands of Americans whose condition today is no different from that described almost four decades ago, in the 1961 *Final Report of the Joint Commission on Mental Illness and Health*: "A large proportion of mental patients at present, as in the past, are not treated in accordance with democratic, humanitarian, scientific, and therapeutic principles. We have substantially failed them on all counts."

It's time for a humane change.