What About the Patient?

Daniel E. Weisburd

Our mental health care system fails to serve the very people whose suffering that system ostensibly exists to alleviate. This article relates the stories of 3 people who fell through the cracks of this system. An alternative approach, the Integrated Services Agency (ISA), has been implemented in California and offers hope to persons with schizophrenia. The ISA approach focuses on the expressed needs of the members it exists to serve, and both members and staff have experienced changes in their roles and expectations. Staff and members have learned that engagement with the "outside world" involves taking risks but that risk avoidance only perpetuates the status quo. The ISA approach rewards growth and patients' being well rather than rewarding docility and illness. Medication is neither ordered nor assigned, but chosen in a collaboration between staff and members. ISAs have returned care to the mental health care system. *(J Clin Psychiatry 1999;60[suppl 3]:38–41)*

Our mental health care system fails to serve the very people whose suffering the system ostensibly exists to alleviate. I found "a bewildering, Kafkaesque maze of difficult-to-access programs for which nobody had continuing responsibility and where standards of quality were nonexistent."[1] Mental health care is a nonsystem, chaotic and dysfunctional, which helps very few people. The system tends to focus on cost minimization, which sometimes means that the necessary medications are not administered to patients who need them because of the greater initial cost. Three examples I am going to cite are illustrations of how our mental health system fails. But there is an alternative approach, implemented in California, that offers hope for persons with schizophrenia.

The first young man, Bobby, is dead, a victim of inadequate care and treatment. While taking an antipsychotic medication, Bobby's weight grew from 160 pounds—he was a gymnast—to 300 pounds. He had seen a doctor previously for 15 minutes, hardly enough time for anybody to know anything about this young man. And he died. This is our mental health care system.

Edward had a history of acting-out behavior. He pushed around a pregnant woman at a dance once, and people said, "He has a problem acting out." Another time, Edward, who is a very big man, chased a driver whose car had grazed Edward's car in a traffic mishap, pulled the smaller man out of the car, and beat him badly. The police were called, and when they arrived Edward beat them as well.

To be fair, Ed was the highest functioning person in the model program I helped to establish, the Village Integrated Services Agency. He earned a master's degree from Stanford University. Still, Edward had given many warnings. He had seen many psychiatrists. He had been working with a brilliant psychologist for 10 years. Who heeded these warning signs? Who did anything about Edward's acting out? Nobody.

Recently, Edward's brother drove to pick him up. Edward walked around to the driver's side of the car and plunged an 8-inch butcher knife into his brother's heart. Edward was a compliant patient; he had been taking an atypical antipsychotic medication religiously. Sitting in jail, taking his medication, Edward explained without betraying any remorse that his brother was evil and had to die. This is our mental health care system.

David Jay Weisburd is my son. Extraordinarily gifted, bright and talented, he was diagnosed as having schizophrenia in 1980, while he was studying at Harvard University. Suddenly the institution that had courted him so vigorously only 2 years earlier could not be rid of him too quickly. My wife and I were willing to spend any amount of money to have our son back. We found, at both public and private institutions, that the needs of the patients were the last to be considered by anyone on staff. The human costs of our mental health system yield to the fiscal balance sheet. Mentally ill people are marginalized by the agencies designed to help them as well as by society in general. They are evaluated on the basis of their deficits, not on the basis of their strengths and positive attributes. People with mental illnesses are warehoused in locked facilities, ostensibly for their own safety.

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When David discovered the Village Integrated Services Agency and gained entry into the program, I requested that he be seen at St. Joseph's Hospital in Long Beach, California. I had had triple-bypass surgery, and David might have genetic tendencies that bore watching. Even though David has smoked constantly since the onset of schizophrenia, he was not given a chest x-ray. David's test results raised a warning flag, but the doctor in charge was dismissive of the danger. When I threatened to investigate the doctor's credentials, he repeated the tests, with worse results the second time.

I contacted my wife's physician, who offered to be David's primary care physician gratis, because it would not have been cost effective to waste time with the voluminous paperwork that would accompany Medi-Cal insurance, and paying him myself would violate federal regulations. This doctor recommended that David take a heart medication that Medi-Cal would not authorize until 2 other, less expensive heart medications had been tried without success.

This is how our health care system works. A valid evaluation of cost effectiveness considers more than the costs of medication. Studies[2–4] have indicated that the true cost of atypical antipsychotic medications, which are originally more expensive than their conventional counterparts, is less than the cost of traditional antipsychotics after the costs of increased hospitalizations are considered.

My son David has been hospitalized many times. He started taking clozapine when it was in phase 3 testing, because he had been refractory to other drugs, but Medi-Cal would not pay for the clozapine. Short of a class-action lawsuit or new legislation, there was nothing to be done. I approached my state senator, and a law was eventually passed, with unanimous bipartisan support, making new medications available. Now David is taking both clozapine and olanzapine. He likes his medications and is happily compliant.

Caring is the sine qua non of mental health care. Ultimately indefinable, it can neither be quantified nor faked. It is not conferred along with academic degrees or professional credentials. In the words of one person with schizophrenia:

> I know so many people who sit on the psychiatric unit look medicated and vacant eyed and the staff thinks they don't hear very much or that they're totally out of it, but that's not so. We're not cabbages lined up on a shelf. We hear quite well and we see quite well. We hear the staff talk about us, as though we aren't there, and we see people walk by without even glancing at us. We are very much there, a part of our minds is keenly aware of what is going on in us and around us but the medication makes our bodies move slowly and stiffly and makes our eyes appear vacant.
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> When we get patients where I work who have that look, I sit and talk with them and look them in the eyes and touch their hands or shoulders. I know what it's like to want to be talked with, and to want someone to look in my eyes and not be scared to touch my hand for fear it is unprofessional. Sometimes all the professionalism in the world can't heal as much as a moment of humanness/humanity.[5]

Mona Wasow, a Clinical Professor of Social Work at the University of Wisconsin at Madison, echoes this young woman's words:

> Our insurance system will pay for professional treatment, whether it works or not. But it will not pay for nonprofessional care, especially when it cannot be quantified and measured.… Third party payers pressure us to take caring individuals and train them to be "professional" so they can justify paying for their services. But the more we professionalize them, the less they can provide the very caring for which they are needed. The other side of the coin is that professionals do have to set limits in order to lead their own private lives.[6]

In 1986, after describing the plight my family faced as we searched for any kind of treatment that would work with David, I was charged by Leo McCarthy, then Lieutenant Governor of California, to assemble and chair the Task Force for the Seriously Mentally Ill. The work of that task force led to a report recommending legislation to establish small, comprehensive, Integrated Service Agencies (ISAs) for those in the state with serious mental illness. Both counties and private nonprofit agencies would bid to operate ISAs under performance contracts with the state. We encountered strong resistance at the county level. County staff resisted competing with nonprofit agencies to operate ISAs and resented the imposition of state-imposed standards. Some local mental health leaders had difficulty accepting the comprehensive human services requirements of the proposed system, a system that would greatly expand long-held concepts of mental health services.

The Task Force originally proposed the establishment of 25 pilot Integrated Service Agencies serving 4000 members across the state with sensitivity to issues of ethnic diversity in the population served. Funding for the ISAs would be capitated. The final bill funded only 2 ISAs. This was, however, a bill that could pass the scrutiny of county mental health agencies. The governor signed this bill into law in 1988, and the Village Integrated Service Agency subsequently opened in Long Beach, California.

Karen Strand R.N., M.N., reflecting on her first 3 years as a nurse and team leader at the Village, notes ways in which both staff and members have adapted to a facility operating on a psychosocial model:

Role boundaries at the Village have been purposefully blurred, resulting in role confusion for both members and staff. "We engage in social activities, have meals together, remember birthdays and special occasions, talk about whatever is of concern…I was not the expert any longer and did not have my role as individual therapist to hold on to."[7]

The Village experience is focused on member desires: In the past, Ms. Strand had always used her therapeutic skills in weekly group sessions to maintain her position of authority and control. The program at the Village was driven by the members' expressed desires. It was no longer a matter of what we had to offer to a client that they could choose from, if they wanted. It was now, "What is it that members want and how am I going to help them achieve it? The collective skills that staff had were…no longer the driving force for activities or action."[7] Ms. Strand found her predilection for therapy sessions pushed to the background, as she focused on helping members to achieve their goals, such as finding an apartment, locating a job, and going to Alcoholics Anonymous meetings.

The Village experience focuses on wellness and health, not on symptoms. Existing systems often provide patients with particular services only when they are sick. At the Village, being well is rewarded. Symptoms are an inescapable part of life for the members, but they are not obstacles to making friends, holding a job, or having fun.[7]

In the Village, risk-taking is encouraged. The old model of success focused on reducing stress, optimizing compliance, and keeping the patient comfortable and acting reasonably. (Witness the number of times David Weisburd was shunted from one care facility to another because his behavior, brought on entirely by an illness these facilities were supposed to treat, was too disruptive for the other patients and inappropriate.) Success at the Village is now measured by quality of life and growth.

Mark Ragins, M.D., who now refers to himself as the "Village Doctor," has also had to abandon unproductive attitudes learned in conventional psychiatric care settings, noting that his role regarding medication is now that of a consultant, helping members to make educated choices about medication and assessing results with them in a model of care that focuses on rehabilitation and recovery rather than illness treatment.

> There are 3 common obstacles to medical collaboration: (1) Some members are using medications to achieve pleasant altered states of consciousness instead of to function better. These members often use illegal drugs and alcohol as well. I try to add substance abuse treatments to my medication visits. (2) Some members are so demoralized that they would prefer to sleep through life and have their feelings anesthetized. I try to separate unpleasant feeling from symptoms of an illness. (3) Some members are so out of touch with reality or in such denial of their illnesses that they are actually legally incompetent to make decisions about their medication. I can only force them to take medication if they are involuntarily hospitalized. Over the long run I think I'm more likely to succeed by building our relationship, by working with them on their goals, by proving myself trustworthy and by caring. [8]

Bruce Anderson and Gina Gross, comanagers of Community Resource Network, have provided ongoing consultation with the Village in values clarification and service-user planning processes. They share their changing impressions of the Village.

> Anderson: The culture of the social service system has conditioned both staff and service users to believe social service buildings are safe, and the community is not.
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> Gross: Everything they were doing in the ISA building could have been happening in the community, but I don't think the staff, as a whole, was ready to believe that was possible. For example, the whole notion of the restaurant was to bring the community into the village. But isn't it simpler from a resource point of view to be doing those things out in the community?
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> Anderson: What's different now?
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> Gross: Some Village staff say that it took time to get to the point where they accepted the fact that life in the community was not something to be avoided…Now [they]…see community life as a positive and worthwhile goal. Just as important, they now say that some risk is an acceptable, normal, and healthy part of everyone's life.
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> Anderson: One thing that the Village has demonstrated is that the staff have to change at least as much as the members, in order for the members' lives to improve.[9]

Growth is not achieved without taking risks, and growth is absent in the absence of risk.

John Forbes Nash, Jr., was awarded the 1994 Nobel Prize in economics for his work in game theory done 44 years earlier. His brilliant and inspired thesis on game theory had led to many honors and accolades. *Fortune* had identified Nash as "America's young star," but he vanished in the late 1950s—there were no published papers, no academic positions. Nash disappeared into the terrifying world of voices and illusions known as schizophrenia.[10]

Carol North, a person with schizophrenia, earned a medical degree while still very symptomatic and has become a world authority on posttraumatic stress disorder.[11]

Tom Harrell, a person with schizophrenia, is a highly respected jazz trumpeter who cut his musical teeth working with such luminaries as Stan Kenton and Woody Herman. Currently a major-label recording artist, he has led his own groups since 1989.[12]

Schizophrenia can strike anywhere, any time. It appears in mathematicians, janitors, musicians, academics, plumbers, school teachers, taxi drivers, and sculptors.

Your own local legislators are not indifferent. They are resourceful and eager to educate themselves about complex, important issues. When they know the will of the people on a given matter, they act. I myself was personally responsible for 5 bills considered by the California state legislature; 3 of them passed, which gives me a higher batting average than Willie Mays.

We can win over a mental health care system whose greed has overwhelmed its ability to see or to reason about

the issues it should be focusing on. We must win, when the quality of life, the very lives of thousands of people, are at stake.

Drug names: clozapine (Clozaril), olanzapine (Zyprexa).

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