

Planning a Community-Based Mental Health System

Perspective of a Family Member

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ABSTRACT: *The parent of a young adult son afflicted with schizophrenia describes his family's experience with schizophrenia and the mental health system. As chairman of the California Task Force for the Seriously Mentally Ill, he outlines the planning process by which a bill was drafted that ultimately may revamp the entire mental health system. Passed by the California legislature and signed into law by the governor, an integrated service system conceived by the determined father of a mentally ill person will now be tested.*

I am tempted to write, from a family's perspective, about supported work as therapy for persons afflicted with schizophrenia. An idea whose time keeps coming around, work offers a positive alternative to mindless empty days filled with cigarettes, coffee, and TV. It is clear to me that the mentally ill, just as much as any of us, need success and satisfaction that comes only from meeting real and meaningful challenges. I have also been tempted to use this space to question why so few support programs for the mentally ill deal with the assets of the persons they serve, the abilities that are still intact. Why do they drone on mercilessly, focused on symptoms and deficits, invariably arriving at outcomes of little consequence for vulnerable individuals whose brains are terrorized and disorganized by profound disease? But instead of that, I intend to use this communication opportunity to offer a few hard-to-handle observations in the hope that you will find yourself challenging what I say or adding some of your own ideas.

It has been 10 years since my son David called me from Harvard University, where he was on the president's list as an outstanding scholar, and said

I can handle it, Dad. I don't want you to worry. I've checked into the psychiatric clinic, and they've given me some medicine. It's the strangest thing. I hear voices, hundreds of them, telling me that everyone wants me dead. It's like all the radios of the world blaring all the stations at once, and it doesn't stop. It jams my brain. God, I hope they can help me.

I remember those words as clearly as if it were yesterday. Scared, yet confident, needful yet capable, the oldest of my children had embarked on a voyage into what is arguably the most terrifying and painful realm of human experience—the uncharted, unpredictable depths of bio-

logical brain disease, *schizophrenia*. How quickly Harvard, perhaps the best and certainly the most self-congratulatory institution of higher learning in our country, wanted him out of there. Knowing what I now know about the disease that afflicts David, I can almost forgive Harvard their haste in abandoning this young man whom they had so aggressively courted because his grade point average and Scholastic Achievement Test scores were nearly perfect and his self-assured entrance essay showed such promise.

I won't burden you with a litany of complaints about doctors and medications, hospitals and clinics, treatment programs, residences, governmental bureaucracies, and the like. The insensitive, often abusive behavior of some who provide "service" is thankfully balanced by the dedicated, resourceful, and resilient behavior of others. You learn how to be grateful for the good moments and the caring professionals.

I found, after a couple of years in this unwanted and demanding experience, that I was so angry and so depleted emotionally and financially that I had to make a conscious change in my own behavior in order that I might survive. As I attempted to locate help for my son, I found, instead of a mental health system, a bewildering, Kafkaesque maze of difficult-to-access programs for which nobody had continuing responsibility or sufficient authority and where standards of quality were nonexistent.

Because I work in the media as an observer of the human condition and a storyteller, I went public with my feelings about all of the issues surrounding serious mental illness and especially about the experience of living with my ill son and searching for appropriate care.

My wife had insisted that our ill son remain at home to be nurtured in the bosom of the family. Instinctively, she refused to cast out her ill son, to abandon a child in need to "them" out there in a less-than-caring world that gave little evidence of concern for his best interests. I admired that loving grit and determination but disagreed totally. Somehow, somewhere, there had to be people and programs and residences capable of offering David more of what he now needed than we in our ignorance could provide. His illness and the behaviors it evoked dumbfounded and frightened us. And, of course, there were our two younger children, a daughter and a son, both in high school, who were suffering psychologically and physically from our ill son's unpredictable antics. Even when he was out of the home during an acute hospitalization, or when he had run off somewhere in a fit

of schizophrenic wanderlust and was living by his wits in the streets of God-knows-where, it was always *David's* needs and "poor David's condition" that seemed to dominate everything and hover everywhere. But the psychiatrists, psychologists, and day-treatment programs we turned to offered processes that had very little relevance to his raging illness and our confusing circumstance—at least in our judgment.

We sensed that something was wrong; something was missing. At first, naturally, we suspected our own judgment. We had no prior experience to fall back on, so we listened attentively to professional talk about structure and lowering of expectations and about how to communicate with an ill person who was experiencing terrifying and distorted perceptions. We were game, we were willing to try almost everything.

What we found was a paucity of ideas that worked. A lot of mystification of process shrouded in polysyllabic argot—appropriately annotated and attributed to source, of course—but when decoded there was a scant yield of a few tangible suggestions about what we might do to make life more bearable for him and, frankly, for the rest of us, especially if David were to continue living in the family home. Our home, incidentally, was rapidly becoming an institution in which David wasn't getting better and we were all getting worse.

Meanwhile, outside of our home, my father was diagnosed as having the most virulent form of leukemia, with a prognosis of six months to live. My mother's cardiologist confided that her heart disease, complicated by diabetes and stressed by my father's sudden grave illness, could snuff out her life at any time. My brother's cocaine abuse, which had destroyed his very successful fashion photography career, was about to take him from the scene. And my mother-in-law was on the verge of the first of three devastating strokes that would leave her bedridden, a veritable vegetable, despite miraculously successful brain surgery. As the family decision maker, I found myself coming to grips with how American medicine delivers benefits to those in need, insured, and capable of paying for the best that can be purchased. It was a soap opera wrapped in a nightmare.

By far the worst of circumstances were to be found in the bizarre, nonsystematic way in which our society pretends to support the needs of the seriously mentally ill. In political rhetoric lawmakers give the impression of attention and concern; our bureaucracies display the illusion of care provided. And, as a people, we seem to accept this outrage as if it were the way things had to be. Hundreds of families have thought that perhaps it was their ill family member's unique symptoms that made the existing housing and the day treatment and the medication less than effective, less than adequate.

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What came as no small surprise was to find parallel areas of neglect in the other profound illnesses that beset my various family members. Housing was one such area. Go into expensive acute hospital care and almost anything you could ask for is available, paid for in large measure by insurance, or out of pocket if you can afford it. But, try to maintain a home for a stroke victim; a heart patient; or a person gravely ill with leukemia, a drug problem, or a brain disease like schizophrenia, and see what you come up against. Far lower cost? Definitely true. But who will pay for the "professional care" needed? The state? No. The federal government? No. The private insurer? No way. Not in most cases. Premium costs would be staggering. The vice president of Blue Cross told me that on the "Today" show. So, without a reasonable flow of capital for *home care*, no trained labor force develops; none exists.

Move your seriously ill family member to a community residence, is what society tells you. "Professionalize" their care in that way. You want to do the right thing. You turn the patient over to a system of care—a nursing home, a convalescent hospital, a skilled nursing facility. And most are a far cry from the squalor of the past. But few, if any, treat people as individuals or deal with infirmed persons' assets as well as their deficits. Fewer still give them private moments of dignity and recognition and some meaningful way to fill the hours of another precious day of life. That seems to have been ruled out some time in the past as not appropriate to the program, or too costly, or too impractical, or too whatever. Watch as I have watched very ill people strain to communicate through an endless procession of meaningless days with underpaid, undertrained staff whose heavy Afghani, Egyptian, Filipino, Pakistani, Salvadoran, and Thai accents give a wonderful, melodic whimsicality to a totally incredulous reality from which death is often a blessed escape.

In my family, the victims of cancer, heart disease, drug abuse, and stroke, all died despite valiant attempts to cure or to save them. The grieving process happened, guided in part by the wonderful nurturing of hospice—a very human, relatively new concept that thankfully came into our lives. Grieving was experienced; it ended; and life went on for the survivors. David's schizophrenia went on also. And he started to be punished for having it. He was jailed for being a nuisance in the community. He was wait-listed for programs that purportedly could help him be otherwise. He was dismissed by doctors because they had tried all they knew and were embarrassed to take more money for more of what hadn't worked. Evicted by residences because his mentally ill behaviors were disruptive for the other mentally ill tenants, he was also discharged from treatment programs for showing the very symptoms of the illness that brought him there in the first place wanting treatment. And we, his family, shagged after him, trying to pick up the pieces, coming to the rescue, looking for the next doctor, the next treatment program, the next residence, the next medication.

There was one day when he was perfectly well—normal, or 99% so. It happened in the hospital, in a re-

search ward at the University of California, Irvine, under the care of a gifted and empathetic psychiatrist, Dr. Steven Potkin, who had obtained permission to try David on the research protocol of the breakthrough medication, Clozapine. I will never forget that day. It was about six weeks into the drug trial period. There were serious risks involved. We had been forewarned. For some patients the medication suppressed the white count, handicapped the immune system, and opened the way for devastating secondary infections that could kill as in leukemia or AIDS. David had opted to try the medication. Anything was better than continuing life in his present condition, he felt. So he gave informed consent, and he really did understand what that meant. His doctor carefully monitored blood levels and kept in constant touch with Sandoz, the drug maker. And then came the day when David stood before me, wide-eyed, a look of wonderment on his face. There were no "voices." He felt clearheaded for the first time in years.

It's as if I awoke from a nightmare, Dad. And I'm so grateful. I don't want to waste a second crying. But I want to tell everybody *this* is really me and I'm back; that I'm not my illness, that I'm David; that I'm not a schizophrenic. I'm a person.

One day out of eight years. I'm sure you can guess the rest. David's white count was crashing. He had achieved the second lowest count of anyone kept alive and on the drug. But he would have to come off the medication that gave him that one good day. We all sat there looking at the doctor. David agreed to stop taking Clozapine, knowing that he would most likely go back into the abyss of schizophrenia, back to other medications that merely masked some symptoms and perhaps even exacerbated others. Bravely he said, "If I've had this one day, then I know others are possible sometime, I hope soon. And I hope I'll remember what this feels like. Please, help me to remember." I live in the hope spawned by that good day. And I have dedicated a major portion of my energies to work with other families who know the pain and disillusionment of having a mentally ill loved one who needs help that is not out there. Families know which professionals in their communities really do care, and they've begun to share that information. Families know when programs for the mentally ill are willing to abandon practices that haven't worked and are willing to strive to create more responsive, more personalized care and support. Families know. Families know that the book of knowledge about the brain and how it works has too many blank pages and that there has to be a genuine and real and major commitment of dollars to research. So what if the toys of technology are here? My son has had his brain photographed by all of them. So what? It is meaningless unless and until we set our goals higher than mere maintenance and documentation, and we can only do that by major intuitive leaps and painstaking scientific "trenchwork" by biochemists, neurologists, psychologists, psychiatrists, and all the rest in a coordinated effort, not

piecemeal and not showcase pilot stuff. Where is the declaration from a would-be president that by the year 2000 we must be on our way toward the exploration of inner space, that most complex region of the physical universe, the human brain? Where is that would-be leader? Ponder for one moment what might be learned on such a quest. Awesome, far beyond NASA's wildest dream, more practical in our lives than all the Teflon and Corningware and irradiated food in squeeze bags, those marvels of the space age! And, please God, let one adventurous pioneering explorer stumble on and bring back visions of what is schizophrenia, so that others may team up and concoct treatments that work and cures—and, yes, even prevention.

We now have 25 Rose Bowls full of persons afflicted with schizophrenia in the United States. Two and one-half million individuals held hostage by the terrorist, schizophrenia, and what do we do? To deal with the most perplexing disease in the medical lexicon, we pay the afflicted one half of the current poverty level income for their room and board, and we give them a token medical insurance that is turned down by most respectable, responsible doctors and dentists in private practice because the rate structures don't make any sense. For example, my son had an impacted and abscessed wisdom tooth and he tried to take care of it himself. He went up and down streets looking for a dentist who would accept his Medi-Cal insurance. None would. He called me in pain. I took him to my oral surgeon who informed me that, although he did not accept that insurance as payment, he would handle the matter after he consulted with David's psychiatrist to be certain that the anesthesia and David's medication were compatible. I paid \$200 for the procedure. My son's insurance would have paid \$20—not even enough to cover the dentist's malpractice insurance for that single complex extraction. Any wonder then why so many seriously mentally ill persons also have untreated physical ailments that further disable them?

Four years ago I was forced to stop complaining and get to work. I met with the Lieutenant Governor of California, Leo McCarthy, and agreed to form a blue-ribbon Task Force for the Seriously Mentally Ill and to serve as its chairman under the aegis of the California Commission for Economic Development, which Leo McCarthy chaired. It was the opportunity I had been waiting for to roll up my sleeves and attempt to do something with the mess I had experienced and observed. Our agenda would be twofold. First, we would look at how the state spends some \$2.5 billion a year caring for the mentally ill within its borders. Second, we would look into the possibility of a major research agenda for the state involving the prestigious and underused University of California system plus such major institutions as Stanford University and Scripps and the panoply of private industrial giants with interests in this area.

I submitted the names of two dozen individuals, distinguished Californians selected carefully for what they knew and didn't know about mental illness and the mental health system. Seven of them were legislators for both

parties and both houses, several were former clients, two were judges, many were doctors and nurses, psychiatrists, psychologists, and social workers, and three were business leaders and management experts—the senior vice president of American Biogenetic Corporation, the president of The Jeans Company, Levi-Strauss, and the vice chairman of Times Mirror Corporation. All of the names submitted were approved and the work began. We were free to examine all issues, without constraint or need to protect special interests, and we quickly decided that it was not our purpose to repair or prop up the poorly functioning nonsystem we had inherited. Instead we would attempt to reform a 30-year-old, fundamentally unsound way of doing things, a way that had earned California, the most prosperous and populous of our states, the ignominious rating of 42nd in the nation when it comes to caring for its seriously mentally ill.

The National Institute of Mental Health financed our visits to model systems in other states, and the California Department of Mental Health provided data and a small stipend for research interns. The California Senate and Assembly also offered some financial support for staff costs, but most of our funds came from private foundations and donations from individuals. And nobody owned us.

At the end of our first year, we issued a controversial report calling for an Integrated Service System (ISS), one that was driven by the needs of the consumer—the mentally ill person and his or her family—rather than the needs of the service provider. It was a system that opened the door wide for the private sector to compete for public-sector mental health funds. In 14 town meetings up and down the state, we asked for comments and criticisms and we defended our proposals vigorously. In dozens of additional meetings with interested groups and individuals, we listened and learned and then drafted a piece of legislation. For the first time in many decades, consumers and professionals trapped in a frustrating, fragmented nonsystem were offered hope and an opportunity to work together in a system that really allowed the taxpayer's money to get to where the need was. An ISS team of 10 skilled professionals would be given the responsibility and the money for services needed by 150 individuals, 7 days a week, 24 hours a day. Along with capitated funding would come clear direction, accountability, and evaluation by an independent evaluator. No longer pigeonholed in an adversarial role, the ill person and his or her family would be involved in every single step of highly individualized treatment planning and would work together as co-equals with the ISS professionals.

Families became the first and most vocal supporters

of the bill. Clients found it to their liking. For the first time in recent memory, the California Alliance for the Mentally Ill and the Network of Mental Health Clients were united enthusiastically behind a piece of legislation that, if adopted, could ultimately revamp the entire existing system of care. Nurses, psychiatrists, social workers, and psychologists came out in support. But, predictably, state and county labor unions and the conference of local mental health directors spoke out in opposition, as they accurately perceived a challenge to their virtual monopoly of public-sector services. In the California Senate and Assembly, 46 coauthors from both parties added their names to the bill. The momentum began to look unstoppable. But one giant hurdle could destroy it all. The state had experienced a \$1 billion tax shortfall, and our bill would cost money, thereby tempting a governor's veto. We weren't asking for much, just three to six pilot systems for from 500 to 1,000 individuals. We had pegged costs at about \$50 per work day for each seriously ill individual. Surely that low figure as not unreasonable. What could you buy for \$50 that would make a difference in the life of someone whose illness was so perverse and difficult? Yet that was what California was spending on its Conditional Release Program for mentally ill persons who had committed a felony and were now being released back into the community—\$12,000 per year per individual, and that program was showing outstanding results. Its recidivism rate was 6%, compared with the general penal population in which 50% to 60% of released felons were back in prison within one year. As a state, were we willing to spend money to help a convicted felon who was mentally ill, yet unwilling to spend it for the care of a law-abiding mentally ill individual? If so, what message were we sending—"Commit a crime and get good mental health care"? To whom shall we attribute that one?

The bill calling for an integrated system of care for the mentally ill of California has now been signed into law by the governor, having been passed almost unanimously by the legislature. The California Department of Mental Health has advised us that, more than likely, there is only enough money for two pilot systems. It is a meager beginning, but it is truly a real beginning of meaningful systems change. The task force can now begin to look at its ambitious research agenda. And, as for my son David, he has just received another eviction notice and has started to keep a journal again, writing about things other than symptoms and programs, voices, and medications. I like to think that is a hopeful sign. Abandoned by our society, as a pitiful thing, because no one knows what to do about his illness, he and I know he is not a thing. He is a person! Families know what I mean.