Speaking out in Public

(2006)

In public I rarely tell people I'm a psychiatrist unless I'm pressed. I've learned that if I tell them they'll look at me like I've grown one of those glowing eyes out of the middle of my forehead, unsure if I have some strange power to see inside them, and then draw away from me. Sometimes they'll come up to me later when I'm all alone or call me to secretively ask me about a serious problem: It might be an elderly alcoholic parent who's losing it and doesn't want to be put away. It might be a young daughter whose school called because she was caught forcing herself to vomit and was talking about suicide to her friends. It might be a teenage daughter using drugs, hanging out with the wrong people and ditching school or a teenage son who just told them he's gay. It might be a sister who won't leave the husband who keeps beating her up because she loves him or a brother with schizophrenia who won't take his medications, wanders the streets and comes by occasionally asking for money, dirty and frightening. It turns out I'm an expert in secret places.

If we're going to be effective mental health advocates, we're going to have to come out of the shadows and speak out in public. Our community needs to know that we're entering a period of massive transformation in public mental health. Although they'd rather we stay quietly out of sight, the changes we're making are going to affect everyone and they should know what we're up to. All over the country a recovery based transformation is underway. California, as usual, is leading the way. We have some reliable funds from Proposition 63, the Mental Health Services Act along with a blueprint for change. We've been planning carefully, inclusively, and very publicly. We have the recovery vision to guide us. It's happening.

It's rare for any major public system to transform itself. Except for being more crowded, more run down, and cut back, school is pretty much the same as it was when I was a kid. So are jails, and courts, and police. So are public libraries and parks. Technology changes, but services don't. I could argue that the last major transformation of a public system was also us when mental health was deinstitutionalized some 40 years ago.

Before you groan, would you like to know how that transformation turned out? I know you think you know – just look at the streets and the jails – but do you really? There was a major study done by Courtney Harding and others at NIMH that carefully found out what happened to the patients with schizophrenia 25 years after the state hospitals in Vermont and Maine were closed. It showed that about two thirds of them recovered (meaning that they didn't have disturbing symptoms or need treatment, they weren't in hospitals, on the streets or in jail, they were working or engaged in other productive activity and they had a social life indistinguishable from their neighbors). How can that be? you protest – just look at the streets and the jails.

But if you only look at the streets and the jails you're going to be missing most of the picture. It turns out there are a lot of mentally ill people. Even if only a small portion are doing very poorly that's still going to be a lot of people and have a big effect, but they're really only the tip of the iceberg. Most of

the iceberg is actually quietly doing well. Because of stigma they're hiding in plain sight as your neighbors and coworkers. How do I know this? Because I'm an expert in secret places.

Built out of stigma and fed by fear a compelling story of the failure of deinstitutionalization has been told to us over and over again. Rarely has the drumbeat of bizarre, dangerous failures been interrupted by the more common stories of success. After a few decades it has become gospel even though it's wrong for most people.

If you're beginning to feel any doubt, consider two things:

First, the rapid closure of the state hospitals in California occurred during the 1960's bottoming out to near current levels by 1970. The increase in jailed mentally ill didn't really begin until 1980 and has been escalating ever since. Why the time lag? Because the cause for the increase in jailing wasn't really deinstitutionalization. It was caused mostly by the war on drugs that began in 1980 and has escalated ever since. Many mentally ill people use drugs and that's why the vast majority are in jail today, not because of their psychosis. Also beginning at the time we became less and less tolerant of poverty and began turning to jail more and more frequently to deal with problematic poor people. Many mentally ill people are problematic poor people and are jailed as a result. (In no housing market in America are SSI payments adequate to afford housing.)

Second, in my experience with homeless and jail diversion mentally ill people, only a minority (I'd estimate about 20%) had reasonably normal childhoods followed by a disabling major mental illness. The vast majority were already impaired in childhood. Many come from abusive and neglectful families or foster care placement. Many were in special education, especially SED (Severely Emotionally Disturbed) classes, have reduced literacy, and dropped out of school. Many have juvenile substance abuse and juvenile justice experience. LA County Jail is often described as the largest de facto mental hospital in the country. Perhaps more accurate would be to call it the largest display case of the failures of our children's services, foster care, child abuse prevention, special education, juvenile justice, and substance abuse prevention systems. (They are actually the failures of our system some 20 years ago. We have no idea if we're doing better or worse now.)

Our transformation plans need to take into account these rarely publicized realities of our present situation.

We attempted to implement deinstitutionalization using the same medical model services and relationships we used in the state hospitals. After 40 years we've learned how to do things better, but mostly in isolated programs. Now with the recovery based transformation we can implement these improvements pervasively. Here are seven changes we'll be implementing and how they'll affect our communities:

1) We're not going to focus just on treating illnesses, but on building lives.

Somehow we've expected that if we handle treating peoples' illnesses other social service systems would handle their other needs. As budgets have tightened we've narrowed our focus more and more.

Bluntly put, the other social service systems have failed us: People with mental illnesses struggle to qualify for Social Security and to spend the money for food, clothing, and shelter, but no payees are provided. Mentally ill people rarely get permanent jobs through Vocational Rehabilitation Departments or complete educational programs through Disabled Student's offices. Mentally ill people have high rates of having their Section 8 certificates withdrawn. They also often have their children removed by the Department of Children's Services instead of receiving family preservation services. Mentally ill people rarely do well with standard health care services, substance abuse services, probation, or parole.

It's not that mentally ill people are incapable of succeeding at these things. It's that services must be adapted to meet their needs to be effective. Mental health systems need to actively collaborate with and support these other social service systems for them to be effective and sometimes we'll even need to provide the services ourselves. We're going to be approaching these service systems to work together and advocate to make it harder for them to ignore mentally ill people.

We're going to keep track of our Quality of Life outcomes (finances, housing, employment, education, legal, etc.) so that we'll all know how we're doing and whether tax money is being well spent. We'll be able to hold each other accountable for building lives.

Focusing on building lives instead of treating illnesses will also dramatically improve our engagement rates. Many mentally ill people don't believe they have mental illnesses (at least not the way our system defines them) and even more mentally ill people don't want our medications and therapies. As a result, they often stay away from us, suffering and struggling on their own, and disrupting everyone else when things go badly. On the other hand, many of these same people would like to rebuild their lives. They will accept charity, but not treatment. They will accept quality of life support services, but not clinical services. If we offer substantial welcoming, charity, quality of life support services, and advocacy we will engage far more people than we do with treatment and rehabilitation alone. This change will likely make the involuntary outpatient treatment argument virtually irrelevant because it will be possible to engage and assist almost everyone in need.

People's lives shouldn't be lived within the confines of mental health program walls, whether hospitals, board and cares, day treatments, club houses or rehabilitation programs. Their lives should be lived in the community. Therefore our staff has to stop hiding with them behind clinic and asylum walls. We have to come out into the community helping them rebuild their lives – supporting them, advocating for them, getting involved directly in their lives.

2) We're going to build on the reality of recovery.

Too much of the history of mental health treatment has been built on the hopelessness of incurability, while the reality is that the majority of people with serious mental illness if given care and support and a full opportunity to return to the community will recover. We know this from hearing from people who have recovered. We know this from the moral treatment outcomes from the 1800s. We know it from Courtney Harding's longitudinal follow-up studies from Vermont and Maine. We know it from the WHO studies of the natural outcomes of schizophrenia in third world countries.

We will create opportunities, not warehousing.

Chronic illnesses don't have to mandate hopelessness. For acute illnesses recovery results from symptom elimination and cure, but for chronic illnesses recovery results from:

- Achieving self-management of the illness
- Maintaining hope and self-image
- Carrying on with life through rehabilitation and adaptation
- Replacing professional supports with natural supports in the community

For acute illnesses recovery is illness-based.

For chronic illnesses recovery is person-based.

Even with symptoms lives can be rebuilt, disabilities can be rehabilitated, adaptations can be made be people and by their communities, and destruction can be overcome. We're going to expect, not illnesses to be cured, but people to recover:

- Functions will be recovered - as in the ability to read, to sleep restfully, to work, to have coherent conversations, to make love, to raise children, to drive a car, etc.
- External things will be recovered – as in an apartment, a job, friends, playing in a band, a spouse, a car, family relationships, stereo, TV, educational programs, etc.
- Internal states will be recovered – as in feeling good about oneself, satisfaction, self confidence, spiritual peace, self-identity other than mentally ill, self-responsibility, etc.

We will create recovery based services and systems.

For people with mental illness to be included in our communities they have to be responsible just like everyone else. No longer will we plead incapacity and irresponsibility to help people with mental illnesses avoid their responsibilities, legal or otherwise. After all, it's a rare person who really doesn't know right from wrong. The vast majority of people with mental illnesses are arrested for drug crimes and even if your voices are telling you to steal and to use drugs, you know it's illegal and should be held accountable. It may be tempting to get out of responsibilities by pleading mental illness, but the cost is exclusion from community life. No one wants an irresponsible neighbor, employee, spouse, or parent. Not everyone, of course, with mental illnesses is responsible, but almost everyone can become responsible. Our job is not to help people avoid responsibilities, but to support them to meet their responsibilities.

We can all learn to deal with our fears and tolerate living with people with mental illnesses even if they have symptoms (after all mental illnesses aren't that dangerous or contagious) if we can support them to act responsibly.

We're going to emphasize self responsibility, wellness, natural supports, and community integration – not professional liability, illness, professional supports, and segregation. We need to build our community's caring capacity not its caretaking capacity.

3) We're going to integrate substance abuse treatment into all of our programs.

Most of the really damaging things that happen to people with mental illnesses and most of the destructive things that they do are a result of drug and alcohol abuse – just like everybody else. It's time for us to stop expecting the substance abuse treatment system to help them for us. They've got a lot less resources than we've got. They've got their own serious problems with stigma. They've got the criminal justice system breathing down their necks. And they just can't handle most of our people anyway. We can learn a great deal from them, especially about recovery – after all they've been at it for a long time - but we need to do the work ourselves.

I don't mean that we'll create special dual-diagnosis specialists and programs. All of our staff must become dual-diagnosis competent and able to deal effectively with substance abuse on a daily basis. We'll also need to move beyond where most people in the substance abuse treatment system are and work with people who are still actively abusing substances, getting into trouble, and not ready to stop. We'll need to master engagement, harm reduction, and motivational interviewing techniques to be effective. We'll have to work on our own stigma to get the work done.

4) We're going to build specialized programs to work with transitional age youth (TAY).

There are a lot of people who first begin struggling with mental illnesses in their youth. There are a lot of children with mental illnesses and emotional disturbances who struggle with growing up. And there are a lot of "throw away kids" heading towards our streets and our jails. We're going to have to be there working to reclaim them to have a real impact.

Sometimes we'll be helping them to transition into adult recovery-based services hopefully bypassing years of suffering and disability and sometimes we'll be helping divert them from adult mental health services entirely as they mature into functioning adults. These are new programs for us and we're going to have to develop the techniques we need as we go, but we have our recovery vision to guide us.

5) We're going to target highly problematic people for intensive assistance

There are a relatively small proportion of people with mental illnesses who are having the most difficulty. They are not responding well to our "one size fits all" system. We're not going to respond by locking them up, even if you highly publicize our worst tragedies and even if you threaten to lock them up in jail if we won't. What we are going to do is give them very intensive, very accessible services in the community designed just for them. That works the vast majority of the time even without additional

coercive powers. We're devoting about half of the first set of new Mental Health Services Act programs to this effort, calling them Full Service Partnerships, and enrolling people not based on our own clinical criteria, but based on what who the community feels is most in need (initially mostly homeless, jailed, and repeatedly hospitalized people).

I can warn you, you're going to have two problems with this approach from the beginning: 1) It won't feel fair. Some people are going to be offered lots of help, including housing and lots of staff attention, and some people are going to be offered very little help; and 2) It won't feel right. In some ways the people who are selected for the most help will seem to be the least deserving. It will work out that people who don't take their medications, abuse substances, are irresponsible, don't take care of their housing, and/or cause trouble by doing illegal things will be offered lots of help while people who are responsibly working with us to improve their lives and recover won't be.

Why would we do that? Because that's what will work to get everyone living reasonably in our community.

6) We're going to openly hire substantial numbers of people with mental illnesses.

We know they will be suspect at first. Even most of our staff don't believe people with mental illnesses can be effective colleagues, but they can. You'll probably make fun of us at first, saying we're letting the inmates take over the asylum or that this just proves we're all crazy, but we'll stick to it. They'll probably need some special training and supports at first – so did Jackie Robinson – but eventually they'll just be a normal part of our workforce.

Believe it or not, there are already lots of people with mental illness working very effectively in our system. Some are open about their experiences and even use self disclosure to help other people recover too and some are still "in the closet." (By the way, you already have valued coworkers with mental illnesses too, but they're pretty hidden.)

We're not going to make it safe for all those people to come out of hiding until we openly hire more people with mental illnesses. Ultimately, hiring people with mental illnesses is the single most important stigma busting thing we can do. If we won't trust them to work effectively, why should you? But when they do succeed – and they will if we keep our expectations and our standards high - they'll have earned your respect and a place in your workforce and our community too.

7) We're going to actively work in our communities to make them more welcoming

One of the main problems with deinstitutionalization is that the community doesn't accept it. Most people still believe that they shouldn't have to be neighbors or coworkers or parishioners with people

with mental illnesses. Most of us still believe they should be put away somewhere, taken care of, and most of all, that we should be protected from them. How do we really expect them to thrive in our communities when that's how we feel about them?

Our communities can do better. We can be fair to people with mental illnesses. We can include them in our lives. And we can even welcome them. The antidote to stigma is not, contrary to popular and professional opinion, education; it's welcoming. To really fight stigma, I'd rather have an employment program at Walmart for people with mental illnesses, so all the staff there could build relationships with them as colleagues and relate to them directly, than give a lecture about schizophrenia to the Rotarians. To truly change the lives of people with mental illnesses, we need compassion not pity, relationships not avoidance, acceptance not ostracism, and inclusion not segregation.

It's not too much to ask for our communities to welcome people with mental illnesses without us having to hire an army of professionals, paraprofessionals, and consumers and their families to care about them. We can all care.

This advocacy and community building work is difficult. We may not be very good at it and there isn't much money to pay for it. Nonetheless, we have to do it if deinstitutionalization is really going to work. If people with mental illnesses are really going to live full lives in our communities, we're going to have to stop being so secretive, come out of the shadows, and speak out in public.

And you're going to have to listen.