

*After Proposition 63 passed there was excitement in the air in the mental health community in California. At first I thought it was just because of the money. After all, we've been chronically underfunded and subjected to budget cuts virtually every year and here was an estimated \$600 million dollars a year in new funds. We had new friends everywhere. Then I went to a planning meeting in San Diego. The ballroom was overflowing with people. The entire hotel was overflowing with people. While some had been drawn by the money, as I listened to the excited chatter and the impassioned questions from the floor, I began to realize something more than money grabbing was going on. Here were mental health advocates, consumers, families, county directors, administrators, and staff of all kinds each with some version of, "I've been in mental health for 20 years and here's our first real opportunity for change in my life. I've been waiting for this my entire career. We'd better take advantage of it and really do something or we'll have no one to blame but ourselves."*

*I began to see that this transformation was much bigger than I had imagined. Not just staff involved, but also many, many others: Consumers and their families, program directors and leaders, system directors, administrators, and auditors, even the community at large. And all of us were going to have to transform ourselves if this was going to work.*

*I put together this booklet to paint a bold picture of the transformation's personal elements and after some editing assistance the Village posted it on our website. I've used it as a lecture in my 1 and 2 Day Recovery Based Personal Transformation workshops. I also presented it as the key note speech at the March 2005 California Association of Social Rehabilitation Agencies (CASRA) conference. They taped the speech and have a DVD available for purchase accredited for CEUs.*

*Although this booklet is both dense and lengthy, as I've traveled around the state working with an enormous variety of people, I've come to realize that every section contains something that will be a real struggle for someone to actually do. Fortunately, I've also come to realize that I'm not in this alone. Hundreds and hundreds of dedicated, passionate people of all kinds are hard at work promoting this transformation. I'm just one of them.*

## **A Guide to Mental Health Transformation on a Personal Level** **(2005)**

### **Introduction**

What if we build a new mental health system without changing ourselves? Will we really be changing anything? It would be as if we built a huge new house, but ended up staying in the old living room watching TV while the new rooms were just for show. Isn't the point of a dream house to create a dream life? Isn't the point of a transformed mental health system to create recovery? Here are some sample concerns:

- What if we create a new employment program, but psychiatrists still think that people with serious mental illnesses shouldn't work because the stress might cause them to relapse so psychiatrists never refer anyone?
- What if we create a new dual diagnosis program, but staff won't use harm reduction or motivational interviewing because these techniques feel wrong to them, like they're approving of drugs and enabling, so very few people who are actively abusing substances are engaged in the program?
- What if we create a new voluntary graduation program, but consumers refuse to leave us because "I like seeing you. Besides, last time when I went to an HMO and relapsed, I lost my apartment and I almost lost my kids. I don't care how many WRAPs (Wellness Recovery Action Plans) and advance directives we do, I'm not leaving."?
- What if we create a new social program, but to make sure no one gets lost or in trouble, staff runs all the activities in the building with an occasional group outing, so no one ends up meeting anyone in the community who doesn't have a mental illness?
- What if we create a supported housing program where people get their own apartments, but parents won't let them move out of the house because "they won't take their medications or take care of themselves. Staff won't be there all the time. There'll be a crisis and it'll all fall back on me. I'm not putting myself through that again."?
- What if we get the funds and a building to create a new homeless assistance program, but the neighbors get frightened and convince the local authorities to refuse to issue the permits to run the program?
- What if we start hiring consumer staff, but the program director isn't comfortable having them over to her house for the staff's annual Christmas party?

### The Vision

Almost 40 years ago, people with mental illnesses were freed from bondage in the psychiatric state hospitals in California. There were little funds available or preparation, but they left believing in freedom even while facing the unknown. There were mixed results. Sometimes it felt like wandering in a desert. But like the Jews millennia earlier, their wandering resulted in considerable wisdom and a shared faith.

Though not the Ten Commandments by any means, the mental health field has gained a lot of wisdom in the last 40 years. The National Alliance for the Mentally Ill (NAMI) has grown and with it has come a technology of advocacy, family inclusion, support and psychoeducation. A consumer movement has grown and with it has come a technology of advocacy, clubhouses, peer counseling, empowerment, self-help, self-determination, WRAP, and advance directives.

Rehabilitation practice has developed, which includes supported education and employment, skills training, and community integration. Psychiatry has generated several generations of medications and therapies including illness self-management. Add to the mix integrated substance abuse treatment and health care, mobile Assertive Community Treatment (ACT) teams, specialized homeless engagement and jail diversion programs, wrap-around care, and supported housing programs.

Our collective wisdom and skills are substantial. Unfortunately, most people with mental illnesses do not receive much of this. A RAND study in Los Angeles showed that only a small minority of people in either a local mental health center or VA clinic received even the most minimal of medications, case management, and family support. We have yet to come to the place where all of this is everywhere – the “promised land.”

Why not? A variety of answers have been suggested, ranging from inadequate funding to reactionary professional guilds, but I think the answer is something far more universal: wisdom on its own rarely generates great changes. It’s too lifeless. Great changes require passion to bring them to life.

Our shared passion can now be recovery. We may wonder why recovery has become our shared passion, why it’s been embraced at both the state and federal levels as the core of system transformation. Why not one of the more familiar passions: healing, caretaking, protecting, social responsibility, civil rights, or even medical treatment? How did recovery become so central?

Partly it’s coincidental. A number of paths – consumer empowerment, psychiatric and psychosocial rehabilitation, 12-step models, civil rights activists, mavericks, and staff using personal experiences – have converged on this one idea. Passionate people from all these paths use the same word, recovery, so they’re working together even though they may mean different things by recovery.

A difficult task will be to keep these diverse people working together in the same direction. There will be a strong temptation for each group to declare itself the sole promoter of the true vision of recovery, try to claim all of the power and thereby alienate the other groups. We all don’t have to agree, but we do have to stay in alignment to keep enough passion to achieve transformation.

Partly it’s practical. Together, these paths deal with many of the most troubling failures of our system: collaborating actively with angry and “noncompliant” consumers; integrating substance abuse; integrating rehabilitation; engaging marginalized populations, especially homeless and jailed people; and decreasing staff burnout. Recovery-based programs deal with these problems more effectively than any other model.

Despite the widespread lack of belief in the documented reality of recovery with severe mental illnesses and the difficulties formulating a concise, widely acceptable definition, recovery has shown a great power to energize and motivate our mental health system.

Recovery energizes us because it reminds us why we got involved with mental health treatment in the first place. People don’t come to our clinics, and their families don’t bring them, because they want stabilization and entitlements; they want recovery.

That's just as true for the staff. I do a staff training where I begin by going around the room, slowly asking everyone to share not what their job is, but why their hearts got them into this field in the first place. An amazing richness comes out and the room becomes energized, filled with respect and awe for the people around us every day. One person recently thanked me and said "I haven't thought of myself that way for such a long time."

For recovery to occur, I'm convinced that mental health services must be given, and received, in a highly emotional way. In general, our present system has blocked all the emotion out of it, building professional walls and boundaries keeping us from each other. "Your job must be very hard on you," our friends tell us. "I don't know how you do it." If we were being honest, we would admit that mostly we don't "do it." We block out feelings. We keep people at a distance. Recovery brings back the energy of our emotions.

Recovery is motivating because it is hopeful. Our present system accepts negative prognoses that were built into our esoteric diagnoses more than a 100 years ago. The word "schizophrenia" itself is enough to cover everyone in gloom. Recovery refuses to accept hopelessness. "A diagnosis is not a destiny." People do get better. Don't give up. Something is going to work. And we're all motivated to keep trying.

As with any great faith, our belief is regularly rewarded. I can't tell you how many people with severe mental illnesses have accomplished things that I knew were impossible. I've seen people get their own apartments, work, even raise a family. Last week, a woman who lives in multiple dimensions, talks to spirits, and believes she can see the future, was closing up after a good day at work and she said, "This is all Dr. Mark's fault. He saw me as someone who could help people as a case worker, and he made me try."

And recovery gives us a whole new way of looking at the world. Instead of focusing on symptom relief or functional disabilities, we focus on rebuilding lives. The MHA Village, where I work, has an annual awards celebration called the Golden Ducky Awards. The awards are given for accomplishments in independent living, work, school, sobriety, caring for family, and community integration. Staff, members, families, and even the community join in the applause. One year, a visiting pharmaceutical representative tearfully told me, "This is what's really important." Our members are no longer pitiful victims of terrible illnesses. They are now clearly successes, and everyone there knows how much courage and work it took to get there. Suddenly recovery can be seen everywhere.

Those who seek to carefully define recovery and establish evidence-based practices to promote it need to be careful they don't get so focused on the technology and wisdom of recovery that they lose sight of the passion of recovery. We need both wisdom and passion to transform ourselves.

Now we stand on a mountainside looking down on our "promised land," maybe not a land of milk and honey, but a land of energy, hope, and clarity. We can actually visualize a mental health system where we practice our collected wisdom and skills and help people achieve recovery. We can begin to see what it would look like. It seems almost close enough to reach out and grab.

Let's grab it.

### The Opportunity

Two crucial events occurred recently that make transformation a real possibility, right here in California, right now. These are the President's New Freedom Commission Report on Mental Health and the passage of Proposition 63, the Mental Health Services Act.

The President's New Freedom Commission Report on Mental Health is important because it gives us an impressively comprehensive, detailed description of what the "promised land" will look like. It converts our dreams into actual plans. The commissions successfully combined our collected wisdom and passion while valuing both. There is a commitment to what we have already learned, to ongoing learning, and to rapidly applying new learning. There is a commitment to recovery as the goal of the entire system, its guiding light.

The commissioners also listened to enough people so carefully that virtually everything important is included. Although there are people who have particular interests that may not have been emphasized, almost all of us are able to embrace the report and be motivated by it. Perhaps most importantly, it is an official blessing of massive change, not just reformation but total transformation. It can serve us well for both inspiration and practical guidance.

The passage of Proposition 63, the Mental Health Services Act, taxes very wealthy people to bring hundreds of millions of new dollars to the mental health system in California. While it's theoretically possible to transform a system without new funds, it's very difficult. It's hard to plan improvements while ordering cutbacks. It takes much more faith and motivation for people to stop what they're doing in order to do something new than it takes to add the new to the old and let the new prove itself before stopping the old. Adding things requires new funds and so has only been possible on a very limited scale until now. Now we have some new funds, so it's possible.

Even still, since our mental health system has long suffered from severe under funding, hands will be extended everywhere begging for needed funds. There are many people who support our current mental health system. They believe that we don't need to change the system; we need to fund it adequately and see this as their opportunity to do so. They will point to months' long waiting lists at clinics; staff with caseloads in the hundreds; extremely short hospital stays and no bed availability; lack of long term care beds; closure of state hospitals, day treatment programs and residential care facilities; and over crowded emergency rooms. They will urge that the new monies be spent there.

However, that is not what the act mandates. The act describes its "purpose and intent (is)...to expand the kind of successful, innovative service programs for children, adults and seniors begun in California." Nonetheless, it will be difficult to push aside hands from so many truly needy, existing programs to use these funds for transformation.

A long-term plan to catalyze system transformation was built into Proposition 63. It supplies a gradually increasing, reliable source of funds so we can gradually build a comprehensive system (in contrast to our

usual need to survive funding vagaries that frustrates any long range planning). We're expected to begin with an extensive stakeholder-driven planning process that will describe our "goal" system that we will gradually grow as funding becomes available. It divides funds into five groups – adult system of care, child system of care, prevention and early detection, innovative programs, and workforce development and training – designed to work together as an infrastructure for an entire system.

The act is designed to create new, transformed services not readily billable to existing funding sources, rather than to provide "match" funds for more of the same. There will be quality of life outcome accountability, pioneered by the AB 2034 program. By building accountability into the system, we can assure socially responsible use of the funds so there is a lower likelihood of having the funds taken away from us in the future.

This is a real opportunity. We must seize it.

### **Taking Transformation Personally**

"Why can't we take care of these people?"

I hear the question in the sadness of the elderly mental health court judge as he shakes his head, upset that another state hospital where he used to send conservatees has closed. I hear it in the desperation of a mother who has moved around the country looking for someone to keep her son with schizophrenia from hurting someone or ending up in jail. I hear it in the plea of a depressed, middle aged, unemployed woman who is homeless because her children are now over 18 and her welfare payments are gone. I hear it in the panic of a teenage mother as she tries to keep her infant from being taken away from her, just like she was taken from her mother, and who can't get a Section 8 certificate to rent an apartment.

It's too big of a question to really think about. We tend to focus pain and frustration on more specific targets, like laws preventing involuntary treatment or inadequate funding levels and cutbacks. But comfort is not readily found there. Forced treatment by strangers is far more often experienced as traumatizing than caring. Local hospitals feel like a battle zone where both patients and staff are frequently attacked. More money seems like a fix, but where would it create caring? In our hospitals? Clinics? Jails? Board and care homes?

We all seem so deadened, so overwhelmed, so buried in fear and paperwork. We've all survived for too long by pushing away people. More of the same can't be the answer. We must transform ourselves if we're going to create caring.

At the MHA Village, when a member (consumer) dies, we have a memorial service. Staff, consumers, friends and family get together to share stories and feelings. Recently, more than 100 of us met at the church sanctuary next door to say goodbye to one of our more beloved members, Steve, who died from liver cancer.

Steve wasn't always beloved. His childhood was marked by beatings, foster care, hospitalizations, and even shock therapy as a teenager. He went on to prostitution, rapes, more beatings, losing his children, homelessness, prolonged psychosis, and finally a prolonged, humiliating state hospitalization. With the Village's support, Long Beach became Steve's home.

Steve's team leader tearfully told us that "he called me his little sister because he didn't have one, and I called him my big brother because I didn't have one." His first case manager, although retired for several years, came to share her old stories. Another staff was funny and tearful, telling us about going to lunch and playing in the Village band together. Even our outcomes director talked about rescuing Steve's cats when he was hospitalized. Afterward, our assistant director said he thought it was great that so many people, especially staff, were brave enough to cry openly. I replied that I didn't think it required that much courage. Our staff is expected to be openly emotional. Steve had just "brought out the best in us."

When MHA Village members die, their families usually aren't angry with us. Generally they are thankful for all the caring we gave to their family members. They appreciate sharing stories and tears with us. They don't threaten to sue us. Often, they donate to the Village. They found the caring they were looking for.

The President's Commission took the view that the system itself is what is terribly broken and in need of transformation. The people within the system, presumably, will be fine if the system is fixed. I don't agree. Both consumers and staff have been affected by being in a broken system for a long time. We've gotten used to things being done the way they always have been done, even if it's not what we really want. The system's culture, as well as the tragedies inherent in this field, have become a part of us.

When I finished my residency, I went to work in a traditional mental health clinic. I began to build new services enthusiastically and somewhat naively. I took the room where patients sat and waited for their injections and turned it into a rehabilitation clinic with medication education, self-help, outings and outreach. I started evening family education sessions, a cognitive behavior therapy group and a panic disorder group. I backed up our homeless services worker to help her get people off the street.

Unfortunately, tragedy struck twice in my first two years. Severe budget cuts drove away almost all the staff. Finally, after months of goodbye parties, legal battles, and protest rallies, the last eight of us, like Alamo defenders, were overtaken. Our clinic was permanently closed. I'm proud that I rescued 124 of my 128 patients by taking them with me to a nearby clinic. That still doesn't make up for the hundreds of clinic patients who simply were abandoned, their cases closed, with nowhere to go.

The second tragedy struck when Robbyn, the homeless services worker and a close friend, was stabbed repeatedly until she died by an unmedicated man with schizophrenia who thought she was the devil. No one could respond to her screams fast enough because her office mate was out interviewing for a new job at the time. Every clinic was fortified with guards and metal detectors as a result.

It will be hard for us to open up enough to transform ourselves since we carry the remembrances of being hurt so many times in the past. But opening up will also be where we find our caring hearts again.

One of the MHA Village's most treasured traditions is to play a "Put Down the Ducky" video for visitors and trainees because it's how we began our own transformation. In the video, Ernie from "Sesame Street" wants to learn to play the saxophone, but he can't because he's holding his rubber ducky in his hand and it keeps getting in the way and squeaking. A number of celebrities urge Ernie to "put down the ducky so you can play the saxophone." Eventually, Ernie is convinced. He finds out that only by putting down something old and comfortable can he do something new and exciting.

A great deal has been developed and written about program and system transformation, but very little about the personal transformations that are crucial for transformation to succeed. This booklet focuses on these personal transformations. Unfortunately, changing people is far more difficult than changing adorable puppets. Many of the transformations I am promoting fly in the face of common practice. Many will be heavily resisted. Some people may not be willing to make these changes. The process will be painful. We will need builders, survivors and healers to lead us.

When I do staff trainings on recovery, many people think they already promote recovery, saying, "Sure, I like it when my patients do well. If we had more resources or more time, like you do, I could do even more." It's only when we move on to team treatment planning exercises, program "recovery audits," and role playing that they begin to see how much change I'm really talking about and how much hard work it will take.

I'm often given the advice to go slow, to begin an incremental process of change, to win people over gradually, because there will be too much resistance if I'm clear from the beginning about how far I think we should go.

I tried to follow this advice when presenting to a county's entire medical staff that had been forced to come hear me by its medical director. After awhile, one of the more hostile psychiatrists stood up and passionately urged his colleagues to "really listen to what he is saying, because underneath it he is trying to change everything."

Before I could respond another psychiatrist more quietly said, "I worked in one of these recovery-based programs for a couple of years. It did change everything and it was the hardest thing I ever did, but it was worth it. It was also the best thing I ever did." One of the nurses countered with, "I went to school too long and worked too hard to get where I'm at now. I'm not giving up my role now." The process will be painful.

I'm not following that "go slow" advice in this booklet. Instead I am following the advice of the President's Commission, which said, "The time has long passed for yet another piecemeal approach to mental health reform." The process to achieve transformation may have to be slow and piecemeal, but our vision must be global and complete.

The goal must be noble, not watered down, for us to face the pain along the way.

### Levels of Personal Transformation

Leaders from the Substance Abuse and Mental Health Services Administration (SAMHSA) in Washington, D.C. have begun to implement recommendations of the President's Commission. They created a number of workgroups to address specific recommendations. I was invited as one of 60 leaders nationwide to a forum that focused on collaboration between mental health services, substance abuse treatment, and substance abuse prevention.

We were given inspiring instructions to be as innovative as possible, to go beyond old ways of looking at things, to break down barriers between us, with one proviso – we couldn't change how SAMHSA operated or break down its internal barriers. Ironically, we followed the spirit of these instructions perfectly. We generated hundreds of new ideas for how anyone except ourselves could change. I can hardly wait until they create a White Paper to tell everyone else how we think they should change.

I believe it was Mark Twain who said, "I'm in favor of progress. It's change I don't like." It's perfectly natural to suggest transformations that make someone else change so that I can more effectively do what I already do. Unfortunately, it just won't work. To achieve true transformation, all of us must change ourselves. We have to stop pointing fingers at each other and start making changes that reinforce each other.

A successful process will have to create transformations at all levels. Here are some of the questions we'll need to answer.

- 1) How will consumers and their families move from adversarial advocacy to collaboration, become more responsible for their own recoveries and less expectant of caretaking and protection, and participate actively in the system at all levels, including employment?
- 2) How will staff make major changes in roles, boundaries, risk taking, empowerment, collaboration, coaching, teamwork, community integration, hopefulness, growth promotion, and work alongside people with mental illnesses?
- 3) How will programs and their leaders create recovery cultures that emphasize hope, healthy uses of authority, community integration, and healing?
- 4) How will systems, their administrators and their auditors build recovery values into the infrastructures and accountability measures and make sure power is flowing up from the consumers' needs rather than down from the funders' requirements?
- 5) How will communities create new coalitions and help people with mental illnesses be integrated into community life?

### **Consumers and Their Families**

I hesitated to begin this chapter for fear I was doing exactly what I'd just criticized – telling someone else how to change. After all, I'm not really a consumer or family member. Unfortunately, when I asked

them, they did the same thing we all do. They told me how I should change. Then it came to me. I already knew the main thing they have to do for transformation to be achieved. They have to actually recover.

### **Needing to actually recover**

Recovery is not just an inspiring belief. It is a very practical process that people have to work hard on. In my view, which I discuss in my “A Road to Recovery” book, there are four developmental stages to the recovery process: hope, empowerment, self-responsibility, and attaining meaningful roles. The result of these stages is recovery. Like Kubler-Ross’ stages of death and dying, each of these recovery stages has particular tasks and achievements for consumers and their families. They are transformed by working on this process.

There are a number of critics who believe this entire venture is doomed simply because many people with serious mental illnesses can’t actually recover. Even a passionate recovery advocate like Fred Frese, a successful psychologist who has recovered from schizophrenia, suggests that while there are some people capable of recovery, there are others who are not, and therefore we should create directive, even coercive, programs for them.

I, too, have met quite a number of people who seemed unable to be engaged in a recovery process. Surprisingly, despite my negative predictions, after a year or more in a recovery-oriented program, most of them were actively recovering and basically indistinguishable from those who began more auspiciously. I doubt most of them would be recovering if I had acted on my predictions and been directive and coercive in the beginning. Therefore, I would side with Dan Fisher, a successful psychiatrist who has recovered from schizophrenia, who urges that we work with everyone in a recovery-based way.

### **Moving from caretaking and protection to self-responsibility**

In important ways, this apparently esoteric argument contains the essence of the recovery approach. For recovery to work, people must be active participants in their own recoveries and take responsibility for their lives. And we must help them do so even when it seems impossible. Why? Because that’s the price tag for the freedom they got almost 40 years ago. Often, the most crucial transformation that needs to occur for consumers (and their families) is to stop looking for caretaking and protection from the consequences of their own actions and to start looking for help to achieve self-responsibility. This is certainly not to say that self-responsibility is a prerequisite for recovery treatment. But it is a major goal of recovery treatment.

Self-responsibility requires a fundamentally different relationship between consumers and their families and the treatment staff than many are accustomed to. Caretaking and protecting are two of the most traditionally cherished reasons people seek assistance with mental illness and two of the most formidable obstacles to self-responsibility. There is usually an underlying assumption that because someone has a mental illness they need someone, preferably a professional, to take care of them and make decisions for them.

Challenging this assumption is essential to recovery. It is often thought that the best time to work on self-responsibility is when the illness has been well controlled for consumers – when staff and family think they are ready. To the contrary, I believe this challenge will be the most effective and long lasting if it is accomplished by supporting people through a serious crisis successfully without resorting to caretaking or protecting. Only then will they really believe it's possible to be responsible even while they are ill.

I worked with a very talented man who has serious manic-depressive illness. Every time he had a crisis in the past, he would be hospitalized and kept safe until he felt normal again. He learned his warning signs and used the hospital very effectively, turning himself over to their care each time. Unfortunately, he hadn't been able to hold a job or complete schooling because of these regular disruptions. He also panicked every time he noticed his warning signs because he knew it meant being hospitalized and losing control.

When he had his first psychotic symptoms with me, I didn't hospitalize him. By talking to him on the phone or in person almost daily, I taught him how to adjust his own medications so he could take care of himself. He chose which days of work to miss and held onto his job. He got through the episode safely, and his sense of confidence and self-responsibility grew.

Most consumers and their families are accustomed to being told that the alternative to caretaking and coercion is abandonment. How often have they heard, "If you won't do what I'm telling you to do, there's nothing I can do."? How rarely have they experienced prolonged engagement, empowering crisis management, or self-responsibility coaching? For people to move away from caretaking and protection there must be credible alternatives available, and too often they aren't there.

### **Moving from antagonistic advocacy to collaboration and mental health employment**

A common response of consumers and their families to lack of services is to organize and advocate on their own behalf. In general, they have found that if they advocate for more of what the system is already doing, the system will support them, but not if they advocate for new alternatives. Advocacy for change is usually seen as antagonistic.

There's a line in the movie "Grand Canyon" where Danny Glover says to a car thief, "We wouldn't even be having this conversation if you weren't holding that gun." Advocates are fearful that if they "disarm" they will no longer be included in the conversation about their own lives. How can they trust that "as consumers, we will define what the system is, rather than have the system define who we are," without their righteous anger. What negotiating power would they have left?

A decade ago, I went to my first Alternatives Conference, organized by mental health consumers, in Berkeley. It was a very large, sophisticated gathering of consumers in a highly charged, "civil rights protest" environment. I hid in the back hoping no one would notice that I didn't have a mental illness. The speaker was dramatic, smart, and above all, angry. "State hospitals are like dinosaurs," he roared. "They are much too big, have tiny brains, stomp on little creatures and do a great deal of harm, eat an enormous amount, change very slowly, and deserve to be extinct!" A rousing cheer went up.

In the afternoon, we broke down into small workshops, and the atmosphere was very different. The speakers were consumers actively working in a variety of self-help programs. The rhetoric was toned down as quietly they tried to deal with the real problems they faced with people they were helping every day. No longer was medication anathema. Collaboration with professionals was desirable. But these consumers weren't "dumbed-down professionals" either. Creative, effective ideas were everywhere: warm line, supported housing, and hospital support visits by consumers, to name a few. Most were new to me. Here was advocacy for change that was collaborative, not antagonistic. Here were people who wanted me to work alongside them for change.

Since then, I have seen that model work repeatedly. In New Zealand, Schizophrenia Fellowship, a family advocacy organization roughly equivalent to our NAMI, runs a homeless assistance program. After a few years of experience they were advocating collaboratively for consumer outreach and engagement workers, "housing first," empowerment, and harm reduction. At California Association of Social Rehabilitation Association (CASRA) meetings here in California, there is also that vibrant, respectful mixing of professional and consumer staff. There are three distinct roles available for consumers and their families working in the system: peer advocate, peer supporter, and peer counselor.

It is usually easier, and more fun, to be an outside revolutionary attacking the system, than to be an inside reformer working within the system. One of the most difficult parts of personal transformation is to move beyond our personal stories.

As revolutionaries, our personal stories of pain and overcoming hardship are powerful tools, sometimes the only tools. We draw passion from our stories and move people to action. But personal stories are not always the best way to design programs, create policy, or even be a recovery worker. What we desperately needed for ourselves or our family may not be what others need. What we cherish most may not be what others cherish. Personal experiences are best used to help us understand other people's stories, not to help them imitate our story. We need to broaden our repertoire so we can help them create their own stories, not just copy ours.

Perhaps the single most important transformative step will be to hire lots of consumers, not just in specialized, protected jobs, but as true colleagues. The experiences of crossing the "us vs. them" chasm, of contributing instead of consuming, of being productive instead of taken care of can powerfully change people. These experiences also powerfully change the "normal" staff. As barriers between us are breached, our ways of looking at people in "our caseload" change forever. No longer can we be as condescending, as dismissive, as sure we should be running their lives for them. As they transform from patients into people, we are forced to change, too.

### **Staff**

So far, recovery programs tend to rely on creating small counter-cultures with dynamic leadership, staff who are different or want to change, and new non-professional and consumer staff. Transforming existing programs with existing staff will require a proactive process of staff transformation to succeed.

New professionals are likely to be graduated with extremely little recovery education or values, so they will also require retraining from the beginning.

### **Believing in and understanding recovery**

There is a substantial body of research to support the reality of recovery for people with severe mental illnesses, but it's not being taught because no one believes it. It hasn't been excluded because of compelling contrary studies, epidemiological research, or even well documented debate. Since everyone "knows" that recovery doesn't happen, there's no reason to learn about it.

These powerful beliefs, like all prejudices, are most often changed by experience, not by reason. Currently, the experience of almost all professionals excludes recovery. Almost all treatment settings are designed to preserve safety in crisis or prevent future crises ("stabilization"). We fund crisis care, teach people to describe their needs in crisis terms, and even think in the "language of crisis." We don't fund recovery support, teach people to describe their needs in recovery terms, or think in the "language of recovery." As a result, we never experience recovery even when we notice that some people are doing surprisingly well.

Last year, I led a recovery training for a group of psychiatric residents who had already heard the data and first person accounts of recovery. I facilitated an emotional discussion where they each told four stories: 1) Describe how your heart got you into the mental health field in the first place. 2) Describe a person you worked with who did very well. 3) Describe a situation where you were an important part of someone doing very well. 4) Describe a situation where you learned something important from someone you were trying to help. Recovery is all around us waiting for us to experience it.

As with learning any new language, the "language of recovery" requires learning the basic rules and concepts, building vocabulary, getting lots of practice, and being immersed with experienced speakers in order to eventually be able to think in it. Very few of us are "native speakers," but many of us have had some personal experience with recovery overcoming our own tragedies. These experiences can make us faster learners if we stop isolating them from our work life. We need staff who think in the language of recovery to lead treatment programs and cultures and make them truly recovery-based.

When we start thinking in the language of recovery, we will start recognizing recovery all around us. Then we can begin to believe in recovery and promote it more effectively.

### **Moving from caretaking to empowerment**

One of the first, and often the most difficult, changes staff must make to promote recovery effectively is to stop caretaking. So much of our natural inclinations and our training drive us to caretaking. Caretaking feels so good. It feels like what we're supposed to be doing. But caretaking often isn't the most caring thing to do. We can't caretake people into recovery. In fact, caretaking often protects people from opportunities to grow.

On the other hand, many people are disabled, fragile and at risk. There can be a real danger, even death. Don't they have a true need for protection? We must learn to care for people, and at times even

protect them, while being empowering rather than caretaking. That's the key transformation. When faced with people who are struggling with their illness and making very poor decisions as their lives unravel, we do need to help. But, we don't need to treat them forcibly, make decisions for them, or structure their lives. We need to guide them patiently to turn their lives around.

An experienced psychiatrist who worked at the MHA Village for about a month said that the thing he learned most was not to take so much responsibility for people. He didn't realize how much he was still being the father taking responsibility for their lives, and that wasn't really being respectful of them. He needed to learn to do more negotiating and planning and less telling people what to do.

I once visited a mental institution in Malaysia where shame and stigma are so powerful that it is very difficult for people to return to their families or communities once they've been diagnosed and committed. The staff responded by transforming their traditional caretaking ward into a self-responsibility ward. The patients increasingly took care of themselves and each other, taking their own pills, cooking, cleaning, and even working in a furniture factory they created at the hospital. This took more staff and money than the caretaking ward ever did, but the result was recovery. Many patients freed themselves so totally from their illnesses that their families welcomed them back. They returned to their lives.

The opposite of caretaking isn't neglect. The opposite of taking responsibility isn't abandonment. Hospitals need to teach how to manage crisis instead of forcibly stabilizing people. Board and care homes need to return to their roots as halfway houses, as places that prepare people to care for homes of their own, not places that warehouse people out of sight. Psychiatrists need to teach people to use medications to improve their lives, not just order refills as long as there's no crisis. If we don't focus on facilitating personal growth, it won't happen very often.

### **Moving from treating illnesses to improving lives**

In the medical model, the illness is at the center of the universe with everything else – work, self-image, family, friends, school, home, legal responsibility, and even a relationship with God – revolving around it. We investigate the illness, make a relationship with the illness (called a diagnosis), and treat the illness, all in the belief that everything else will come into line if the illness is well cared for. Cure is the ideal, and recovery can't even be seen.

Like it was with the pre-Copernican view of the universe where the Earth was at the center and everything else revolved around it, nothing fits quite right. Symptoms don't actually predict disability. Removing illness barriers alone rarely leads to accomplishments. Placebo responses, non-compliance, lack of insight, poor treatment relationships, and surprising remissions all defy clear explanations.

In the recovery model, the people are at the center with everything else including, often quite importantly, the illness revolving around them. We investigate their lives, experiences and beliefs, problems and disappointments, hopes and dreams, sufferings and joys. We make a relationship held together by shared emotions. And we help them recover a life directly.

In early recovery programs, there's been a tendency for psychiatrists to be seen as the embodiment of what most needs to be changed and left behind. We're the ones with all of the training in the medical model. Not surprisingly, many psychiatrists find themselves antagonistic to the recovery model before they even have a chance to experience it. As programs mature, they realize that recovery requires more involvement of psychiatrists, not less.

Psychiatrists have to be part of the welcoming process and build a relationship with people instead of medicating strangers by reviewing their charts. We need to be integrated into the treatment team and program culture to avoid poorly treated illnesses from becoming an unnecessary focus. When psychiatric medication is used collaboratively and targeted directly at life goals, it is often a powerful part of the recovery process; many consumers say it's the most important part.

Many staff (and many funding sources) struggle with helping people directly with their lives. We ask, "Is this what I went to school for?" while we're helping someone grocery shop or waiting interminably at the Social Security office. We feel comfortable running a social skills training class, but not actually going to a club with someone to encourage them to ask someone to dance. Nonetheless, it is usually more effective to help someone get an apartment or a job by actually doing it with them, teaching as we go, rather than by having a therapy session to talk about their fears.

Perhaps the most serious problem with our present system is that we fail to engage with many people with serious mental illnesses. They often complain that we're not really helping them or that we're not really listening. They tell us that they don't need treatment; they need a job or an apartment. This problem is dramatically reduced when we move from treating illnesses to improving lives. Suddenly, we're on the same page they are. We're "meeting them where they're at." We're welcoming them with both charity and treatment.

I was taught that the beginning of a good treatment is a good diagnosis. I no longer agree. I think the beginning of a good treatment is a good relationship. A diagnosis can come later. First, I need to connect with someone and build trust by helping them directly improve their life.

### **Moving from detached expert to emotionally engaged guide**

When people first get a serious mental illness it can seem as though it literally swallows them up. Their family is devastated; their job and schooling gone. Friends disappear. Self esteem, confidence, social roles, even God, recede into the distance. They become a schizophrenic. The world they know is replaced by a new, confusing landscape of suffering.

At that point, we usually offer them a professionally approved map, with information like "schizophrenia is a biochemical imbalance in your brain's dopamine system. It may have a genetic basis. Taking medications and learning better coping skills can help you reduce the symptoms" ...and so on. You may think that's a good map or a bad map, but generally it's helpful to be given a map when you're wandering lost and confused. It just isn't the same thing as having a guide walk alongside you. Instead of dispensing maps from on high we can get down and, like Virgil walking alongside Dante through the nine levels of hell, comfort people, hold their hands, and help them through.

Some of us can be good guides because we've been through hell ourselves, though maybe not exactly the same hell. Some of us can be good guides because we've shared the journey so many times before and learned from each traveler we've accompanied. In either case, the role of guide requires more emotional involvement than we're used to. A good guide can see the world through a companion's eyes. A good guide sometimes lets the companion be the guide. A good guide is changed by each trip. But we weren't taught how to be good guides. We were taught how to be map dispensing professionals.

### **Blurring boundaries and role definitions to increase healing**

When I was a resident, I had a patient who said he was very uncomfortable in my office at the clinic because he felt I was controlling the energy in the room. "Can't we go bowling or out somewhere like friends and really talk?" he asked. My supervisor explained how he was being manipulative and trying to undermine professional boundaries and if I went along I'd lose any ability to help him. I insisted on my office, and he dropped out of the clinic. My supervisor told me that some patients just aren't ready for treatment. In fact, if I would have collected the clinic outcomes, I would have found that most people, including the demonstration patient being treated by my supervisor, weren't "ready for treatment." Maybe we weren't ready for them.

My supervisor was taught "the rules" with voluntary patients in a private practice psychoanalytically-oriented setting. He also saw people with serious mental illnesses in long term hospitals where they couldn't chose to leave. He then passed the rules on to my generation. These rules don't work very well in community clinics that serve people with serious mental illnesses and impoverished, fragmented lives who can drop out.

Many experienced staff know this and, because they've figured out what works, have developed their own personal styles and quirks that they wouldn't want their old supervisors to see. They disclose personal information, give their patients food, hug them, help with practical problems, take on multiple roles, and even make home visits. They've become "closet" recovery workers without realizing it. They need to be teaching our next generation.

The boundary rules were created to make sure neither patients nor staff were hurt. We don't want sexual contact, assaults, exploitation, or emotional damage. Since these are real dangers, how can we break the rules without unleashing enormous problems?

There are transformative answers. We can reduce "us vs. them" distinctions and promote more self-responsibility, instead of relying on segregation and armed guards to protect us. We can work in teams in open areas where we can protect each other physically. We can share our feelings with each other and be there for each other. We can create therapeutic milieus where caring for each other is more important than secrecy. We can create a strong emotional matrix with multiple intertwined relationships where we can all be emotionally vulnerable more safely.

But it's hard to do much unless we face our fears first. Many staff have been traumatized by the people they work with, either emotionally or physically. Many of us carry scars. Many of us have learned to distance ourselves from the people we're helping. We can do better.

To truly heal someone else, we have to let them get emotionally close to us, get under our skin, and change us too. We can be helpful without going that far. We can hand out pills. We can do case management. We can give advice. But we can't heal. Recovery is a healing process and to achieve it requires emotional closeness. Although it may sound surprising, I think that allowing ourselves to get emotionally close to others may be the most difficult transformation for us to achieve.

### **Moving into the community**

When we closed the hospitals and deinstitutionalized the patients, we hoped they'd build lives in their communities. We just weren't sure we wanted to be in their communities with them. So we brought our hospitals with us. We set up day hospitals, follow-up clinics, and partial hospitals. We brought our charts, our multidisciplinary teams, our roles, our entire culture. And then we locked the doors and let the patients in one at a time to make sure we were safe.

Most people with serious mental illnesses have almost no money. They're forced to live in poor, dangerous neighborhoods. We'll come out of our buildings if there's a psychiatric emergency. We'll write a hold and have the police or an ambulance take them to the hospital where we're in control. But what if they just need day to day help? We recommend a board and care home or suggest that maybe their parents could support them. We'll give their families psychoeducation classes if they come to the clinic. If we really want to help them build lives in the community, we have to leave our buildings and be in the community with them.

If we're too frightened to visit them in their homes or walk with them as they take their children to school, how much practical help can we really be? We can't have much credibility if we won't step into their world even briefly.

One strange thing that happens if we leave our offices is that we begin to respect the people we serve even more. We see what they go through every day. One home visit is worth a dozen office-based assessments if we really want to understand someone. Sometimes our MHA Village staff comes back in tears. Another strange thing that happens is that people we serve begin to respect us more. We show that we care enough to leave our offices and see what their world is really like. One home visit is worth a dozen office-based sessions if we really want them to know we care. It's not just about our paycheck. They actually are important to us.

Sometimes our job is to help people get along better in their communities and sometimes our job is to help make their communities better places for them to get along in. When we leave our offices and see what their lives are really like, we're often shocked. That's the first step to us becoming good community advocates. If we see their lives for ourselves, we just might get angry enough to fight for them.

### Programs and Their Leaders

We've had a lot of staff come to the MHA Village for immersion trainings. They often leave inspired and energized. Unfortunately, when they return to their jobs they often find little support for transformation. Their enthusiasm withers. They may hang on, trying to create change all alone. But, recovery is most effectively promoted in a communal environment, not in a private office. Staff can't be effective working alone. They need support from their programs and their leaders to succeed.

#### Treating staff the way we want them to treat consumers

If we expect staff to promote hope, empowerment, self-responsibility, and meaningful roles in consumers, then supervisors must promote hope, empowerment, self-responsibility, and meaningful roles in their staff.

For most supervisors, this will be a substantial change. Do they believe staff can grow or do they focus on staff's shortcomings? Do they give decision making and program funds to staff to help people as they choose? Do they believe all staff are experts in something and "chiefs" of something? Do they encourage responsible risk taking or risk avoidance? Do they give staff real power? Do they support other, nonprofessional parts of staff's lives? Do they fight for staff when they're out in the community advocating for consumers? It's a lot to ask if we start listing everything staff really need to help people recover. It's a lot more than they're used to getting.

There are a variety of supervision techniques. Generally, leaders are most successful when their supervisory style matches the product they are creating. For example, a production oriented business is well served by a production-based supervision style that includes production targets, incentives and efficiency measures. A military operation is well served by an authoritative, order-giving style that is intolerant of dissent or discussion. A medical hospital is well served by doctors having lots of authority and demanding obedience from less educated support staff. A psychotherapeutic clinic is well served by having experienced therapists do supervision of less experienced therapists in an emotionally supportive, self-discovery style.

What about a recovery-oriented program? Supervision should follow the same style as the practice. Supervisors should reduce the "us vs. them" distinction with staff. They should supervise by working alongside staff on practical daily life problems to "meet them where they're at." They should take on a multitude of roles, including encouraging staff to lead them at times. They should intentionally blur boundaries, create emotional connections with staff, and connect outside of work sometimes. They should be self-disclosing of their own humanity. They should let staff learn from mistakes while supporting their growth.

Supervisors also should focus not just on the supervisor-staff dyad, but more broadly on the matrix of supporting relationships in their programs. It should be clear by now that recovery must be a communal, team effort, not a pseudo-private practice individual effort. We need to work together to be welcoming, to sustain multiple healing relationships, to keep each other safe, to support each other emotionally, to ensure availability to give practical help when it is needed, and to integrate our efforts.

It takes a community effort to create a recovery-based treatment community. Beginning with the first planning stages, supervisors need to include line staff, consumers and families, rather than make decisions and give orders.

### **Creating a recovery-based culture**

There are four dimensions of every program: individual practice, group programming, individual values, and group culture. We hear a lot about evidence-based practices, but very little about evidence-based programs, values, or cultures. Leaders have a responsibility to build their agency's recovery program from individuals' recovery practices and to build their agency's recovery culture from individuals' recovery values.

One of the most powerful things about the MHA Village is the alignment of all four dimensions. The effectiveness of our culture is built on four crucial recovery values: hope, healthy uses of authority, healing, and community engagement.

Hope is defined as believing something better is possible. For consumers, goal setting is an act of hope. For programs, a mission statement is the equivalent act of hope. It defines the better future the program is working toward. Some consumers don't take their goals very seriously. Goals are just something to write down for appearances, not a real action plan. Some programs don't take their mission statements very seriously. Some programs think they're lucky just to survive each set of cuts, avoid negative press and liability, and keep from getting buried under bureaucracy and paperwork. They're too busy treading water to look forward and dream.

Many of our programs are headed by managers, not leaders. True leaders look around at their downtrodden followers and tell them, "I have a dream." They create cultures of hope, purpose, and vision. They move us forward confidently into an uncertain future.

Recovery requires empowering consumers to make decisions and take actions to improve their own lives. The key cultural point regarding authority is not that decisions need to be made by people with mental illnesses, but that people of all kinds need to make their own decisions. It is no more preferable for a consumer and family advisory board to give orders to the program's psychiatrist than it is for the psychiatrist to give orders to patients.

Empowerment is about autonomy and mutual respect. A good leader sees talent and gifted people to be enjoyed and respected, not underlings who need to be structured, controlled, incentivized and monitored. A good leader gets authority not by demanding it, but by being given it freely in genuine gratitude. Power is not a zero sum game. Generally, the more you give away, the more you get, and everyone benefits.

Many people are drawn into mental health work because of personal experiences. We tend to be ashamed of this and hide it, fearful of derogatory jokes and comments about our mothers. We're afraid of being seen as damaged goods more invested in our own healing than healing others, as going into the field for the "wrong reasons." Yet these wounds and triumphs are often what drives our hearts, what

feeds our motivation, what makes us care for another day. Still, we hold back, aspiring to true professional detachment, hiding the most healing parts of ourselves. We burn ourselves out, not by feeling too much, but by trying not to feel. And for what? To be sure we're the "normal" ones?

A healing culture doesn't glorify suffering by insisting that "you can only help if you've been there yourself." It glorifies the ability to have your "heart go out to someone." We can admire a staff who rescues a consumer's cat or who is moved to tears by bringing Thanksgiving dinner to a lonely person's hotel room. We don't need to know about the staff's traumatic childhood, long ago but not forgotten. A healing culture is where hearts freely go out to each other, not to demand reciprocation or even change, but because we're open enough to each other to be touched.

The core of the dream of deinstitutionalization is for people with mental illnesses to live successfully in our communities, without segregation or prejudice, to be accepted as our neighbors, to find their niche. To achieve this dream, our programs must also be accepted in our communities. We must develop our own niche. Too often we try to gain acceptance for programs by selling out consumers. Leaders need to gain acceptance by developing connections with the community, not by promising to segregate and control people with mental illnesses for the community, but by promising to support our consumers in the community.

The community doesn't need us to protect them from people with mental illnesses. They need us to break down barriers and connect people.

### **Systems, Their Administrators, and Their Auditors**

In some ways, the challenges to transformation seem to grow larger and larger the further up the levels we go. Many people who can visualize individual programs becoming truly recovery-based despair at the thought of system transformation. It almost seems to me as if the decades of mistrust are hardening into demonizing mental health administrators. They're the ones we most expect to block real change. We need to reach out despite our mistrust, because in the end transformation can only succeed if every level transforms.

#### **Moving from directing to shared responsibility**

Our present system tends to create a damaging power struggle between the programs and the system. The system tends to try to assert its authority by giving programs directives, not by eliciting a sense of shared responsibility. Our programs tend to resist and avoid the system. We need to be more considerate of each other's needs and work together more.

A number of years ago, I worked at a county-run clinic. Our director felt that county administration was in general detrimental to good care and did his best to shield us from its influence. He proudly deflected away as many of its demands and directives as he could. One day, just before a MediCal audit, the binders that held the MediCal stickers disappeared, frustrating the auditors. That wasn't very responsible of us. About a year later, faced with severe budget shortfalls, our clinic was closed and the

few remaining staff scattered, without making any arrangements for the people we were serving. That wasn't very responsible of the system.

If transformation becomes merely a weapon in the ongoing power struggles between various stakeholders, we will have failed. It is likely that power will be distributed somewhat differently and flow differently in a transformed system, but that is not the goal of transformation. Recovery is.

### **Moving from system-centered to person-centered**

While consumers, families, staff, and programs struggle with moving from illness-centered to person-centered orientations, most administrators are coming from an entirely different perspective, a system-centered orientation.

Most organizational charts of mental health systems do not have consumers or their illnesses on them. They chart the infrastructure needed to keep the system functioning. The administration is responsive to the demands of funders, financial auditors, labor requirements, legal mandates and restrictions, insurance needs, liability protection, licensing boards, safety commissions, and probably many others I'm totally unaware of. Their focus, understandably, is not on treating illnesses or helping people, but on running a mental health system. The programs aren't seen as the products of their efforts. We're the expenses. We're the sources of risk, liability, audit exceptions, worker's compensation suits and accounting errors.

Every day, if administrators are good, they fix the problems we create so the system can survive another day. But they get so little gratitude or cooperation from us. We fight them every step of the way and claim they're destroying our programs, instead of thanking them for saving us. Given the strangling web of requirements they work in, how can we really expect them to make major changes to help us change? And yet they must. And we must help them do it.

For every new recovery practice we implement, whether it is becoming people's payees, driving them in our cars, handling people's medications, cosigning apartment leases, employing consumer staff, selling their products, buying school books out of petty cash or giving out sack lunches, there will need to be new administrative practices to support them. There will need to be new negotiations between people's needs and administration's requirements.

The personal transformation for administrators will be to put people's needs first, because there's no real reason to save the system if it doesn't meet people's needs. Administrators need to work hard to figure out how to resolve administrative problems so we can do the things we need to do, not figure out how they can stop us from doing things that create administrative problems. They even may have to advocate for changes in the web of administrative requirements to free us. The challenges will be enormous, but they must be faced. We must become person-centered instead of system-centered if we are to become a recovery-based system.

### **Moving from auditing to advocacy**

There are two distinct tools for promoting accountability: auditing and advocating. They tend to be very different. Auditors tend to count objective measures that are documented, for example, units of service or contents of chart notes. They tend to be concerned with making sure that regulations from above are followed to ensure funding and reduce liability. They tend to be “accountant types.” They measure success by documentation compliance.

Advocates tend to respond to individual or class action grievances, for example, poor accessibility of treatment in clinics or jail, inability to access General Relief or SSI benefits, or mishandling of conservators’ funds by the Public Guardian. They tend to be concerned with making sure programs are improved so that people’s needs are met. They tend to be “lawyer types.” They measure success by service satisfaction.

Our goal is to increase the amount of power flowing upward from consumers – to become more person-centered – and to decrease the amount of power flowing downward from regulations – to become less system-centered. So, we should have the bulk of our accountability done by advocates instead of auditors.

I heard a presentation by a group in Philadelphia. There was a class action suit against a state hospital for abusing and neglecting patients. They negotiated a settlement whereby the state hospital was closed. Money was mandated to be used for intensive community supportive services for patients who were in the hospital at the time and future patients who would have been transferred there if it hadn’t been closed. A commission of consumers, family members, and community members was established to investigate grievances and to ensure that the money was used for the intended purpose. The commission had the power to instigate program closures and staff firings if consumer needs weren’t being met. Advocacy can be a productive niche for previously excluded adversaries if handled properly.

#### **Creating externally valid accountability**

A long time ago, I was on a committee to restructure the quality assurance department of Los Angeles County’s Mental Health Department. One staff proudly reported that a chart review at one clinic showed that after substantial effort it had improved its quality of care. I disruptively interjected that the staff actually had no idea if the quality of care there had changed. All he really knew was that he could bully the clinic into spending more time on charts to make it meet his specifications. No one had actually talked to consumers, families, staff or community members. They sat in a room grading charts according to a checklist. We need administration to deal directly with people, not just paper.

A key problem is that administrative directives to programs bear little resemblance to the products anyone outside of administration values – not consumers, families, staff, programs, or even the community. There is an almost total disconnect. No one outside of administration is clamoring for more detailed charting or accounting.

The upshot is that it is difficult to motivate programs to follow administrative directives by appealing to shared values or mission. Administration is forced to rely almost entirely on fear to motivate programs. They have become very sophisticated at creating a culture of fear by threatening funding; playing “good cop – bad cop;” varying elaborate, imprecise rules that come from unreachable sources so no one can

be sure they're safely "in compliance;" threatening larger audits and occasionally even civil or criminal charges; using informants and whistle blowers; and replacing program leaders who try to shield staff and consumers from this culture of fear.

Overall, it has been very effective. I've heard estimates that programs spend about 30 percent of their staff resources to respond to administrative requirements instead of to help people. That's a lot of compliance, but it's generating little of shared value.

We need to create accountability measures that have external validity, measures that people outside of administration care about. In general, outcome accountability is preferable to process accountability. Quality of life outcome measures, like those implemented in the AB2034 programs, are a good start. These measures document the same outcomes that the MHA Village rewards in our Golden Ducky Awards: housing, employment, school, sobriety and finances. That's what's important to people.

Another promising approach is to track progression through stages of recovery. Wouldn't it be nice to measure the recovery process we actually want our system to create? MHA is in the final stages of developing this type of recovery tool. There is a role for process accountability as well, but idiosyncratic mandates need to be replaced as much as possible with evaluation of desired program elements. Let's grade programs on their welcoming, charity, treatment, rehabilitation, advocacy, and graduation practices instead of on their charting.

Administration needs to engage with the community as well. Ultimately, we are accountable to the public who pay for our programs. We sometimes forget that the web of regulations is intended to represent the community's needs. Unfortunately, those needs have been distorted beyond recognition by the Legislature and generations of bureaucrats. We need to reconnect more directly to the community's needs and hold ourselves responsible to meet them.

No more saying we'll only treat certain types of Axis 1 diagnoses, when it's obvious we're turning away people that are disabled. No more saying, "I'm sorry you're homeless, but our next appointment is in six weeks. How would January 8 at 1:30 be?" No more telling distraught families, "We can't do anything if your brother won't come in to see us unless he's dangerous." There is no law against outreach. Instead of coming with an ambulance and restraints, we can come with a lot of listening, some resources, and a willingness to meet people where they're at.

At the MHA Village we try to respond directly to our community's needs. We can, and do, show up at the library when a librarian calls concerned about a homeless man pacing around, talking to himself and upsetting everyone. We can, and do, show up at jail to meet people before they're released, pick them up and pay for a room. When police get a call at night about a young woman wandering around confused they can take her to a hotel at our expense and leave us a message so we'll pick her up the next morning and work out a plan.

If we expect communities to fight NIMBY and accept us, administration has to hold us accountable for delivering services that speak directly to the public.

## Communities

When we truly try to move from treating illnesses to improving lives, we find ourselves increasingly involved with the community. Treating illnesses tends to mean individual or group treatment, prescriptions, therapy and values of privacy and confidentiality. Improving lives tends to mean building meaningful roles in the community. One thrives on isolation from the community. The other requires inclusion in the community. Promoting recovery has a way of creating a ripple of activity from the consumer out into the world.

I recently received a passionate e-mail that read, “Do staff and consumers believe in empowerment and self-determination? In therapy, of course ...when they return to their miserable existence and find out that there is no self-determination they lose faith and become more frustrated. The majority are not stupid, their emotions are impaired but they feel and perceive with all their senses; that makes their emotions further impaired. Give me the power to change the environment where my clients live, heal their physical injuries and find others who do not offend them and I will heal them.” Clearly, our work should not end at the edges of our therapy offices.

### **Welcoming and including people with mental illnesses into our communities**

One of the great difficulties with deinstitutionalization is that many people in our community never agreed that people with mental illnesses should live as our neighbors. They still want us to “put people away.” We’ve found ourselves both apologizing for our inability to do so and commiserating on how unreasonable the commitment law is, instead of assertively defending the rights of people with mental illnesses to live among us and actively supporting them to do so successfully.

I predict that one of the great difficulties with recovery will be that many people in our community never agreed that people with mental illnesses should be responsibly managing their own lives. They still want people to be taken care of and decisions made for them “for their own benefit.” This time we need to find ourselves assertively defending the rights of people with mental illnesses to live among us and actively supporting them to do so successfully. Once we’ve transformed ourselves into believers, we need to work together to transform our communities. Fear will be our greatest obstacle.

Many people with serious mental illnesses say that they are more handicapped by stigma than by symptoms. This isn’t usually denial or projection; it’s the experience of the unwanted. Most people think that the best antidote to stigma is education. I don’t agree. I think it is positive emotional connection with people we’re prejudiced against. Breaking down barriers breaks down stigma. At a recent workshop, one woman suggested that an effective anti-stigma program would be a job placement and coaching program so a variety of business people could have positive experiences of people with serious mental illnesses being productive workers.

If we can effectively reduce the fear and stigma, welcoming becomes possible. We will find ourselves working to increase the “caring capacity” of our community instead of the “caretaking capacity.” It’s a different kind of responsibility than the public is used to.

Like many communities, Long Beach – where the MHA Village is located – faces an ever worsening shortage of affordable housing. Our housing coordinator, who was one of our homeless members several years ago, has connected the Village to dozens of local landlords. She builds a personal relationship with them, tells her own story, promises her support when there are problems, and gets them to rent to our members.

At our Golden Ducky Awards, the coordinator has landlords present awards for “living independently for the first time in your own apartment for a year” to their tenants. The landlords are proud of their role in helping people recover. Our coordinator has increased the “caring capacity” of the community in a very practical way. Not all members need that extra support from landlords, but some do.

Another staff member, who used to help run the Long Beach jail, is our community organizer. He gets our members involved in positive ways in the community. Together they plant trees, clean up our neighborhood, participate in an art walk, and even shave their heads to raise money for childhood cancer. People see our members in a whole new way, and stigma is reduced. He also brings people from the community into the Village for a tour and lunch at our consumer run café. They never leave feeling taxpayer money is being wasted at the Village. Their eyes are opened to new possibilities. So are their hearts.

### **Creating coalitions to promote socially responsible mental health**

The planning process for the Mental Health Services Act acknowledges that there must be widespread community involvement for recovery transformation to succeed. We want to include stakeholders that aren't used to being listened to and included. On one level, this is because we have predicted that transforming and expanding mental health services will save other public systems hundreds of millions of dollars. We'll need them to help us accomplish that savings and vouch for our success to safeguard our ongoing funding.

On another level, we need them to continually remind us how what we do affects the community and how we need the community for people to recover. If we are to stay accountable and if we are to forge an ongoing collaborative relationship with our community, we must stay connected. The stakeholder groups need to continue as coalitions, advisory boards and oversight commissions to promote socially responsible mental health. We can't close the door on our community and hide behind a wall of professional expertise and confidentiality.

This transformation includes everyone.

### **Implementation**

What if we build a new mental health system and it changes us? What if we find out people can do things we thought were impossible and we can help them do them? What if we find out we can do things we thought were impossible and others can help us do them? Maybe we'll even expand what we dream about doing.

I've begun leading recovery transformation workshops around the state related to the Mental Health Services Act. I begin by asking participants to write down the single thing they would like most to see done. What are they most passionate about? What would they fight for?

At one workshop, a table of participants wrote down that what it wanted most was more one-on-one therapy. Toward the end of the day we did an exercise where participants designed a recovery-based system. I asked each table to share its favorite program transformation. I was surprised that this table wanted to create an in-house employment program, even though its goal was "to help build self-esteem" rather than the more recovery-oriented "to build meaningful roles."

Close enough. People don't have to change everything before we begin building a new system. They just have to be open enough to try something new, like an employment program, and pay attention to what happens. I'm sure that, once they start, they'll figure out that jobs do a lot more than improve self-esteem. That will change them some more. It's a synergistic process.

Our building process should promote that synergy. If we attend to each of the four dimensions (individual practice, group programming, individual values, and group culture) and don't let any one get too far out ahead or too far behind, we'll transform more easily and more effectively.

I talked to a leader of the recovery-based system transformation going on in Phoenix. He described the steps the system had taken and was working on. It began by increasing recovery awareness and enthusiasm and emphasizing a commitment to recovery. Then it carefully trained and hired hundreds of consumers to work alongside staff in every program. Several programs were targeted to be pioneers in transformation, and staff were solicited to work in them. Extra resources and attention followed. The next step was to build employment programs.

Now the Phoenix system is working on fully staffing programs with permanent psychiatrists, instead of temporary locum tenens, and integrating them into programs. Next, it will hold people accountable for quality-of-life outcomes and tear down the metal detectors and glass barrier walls. This isn't a blueprint for everyone, but I do think it's a good example of thoughtfully promoting personal and programmatic transformation step by step.

As we transform our system, leadership will be crucial. People need to be listened to and respected. Their fears have to be acknowledged and responded to. People won't give up the protections they have unless they see the downsides of continuing them and have credible new protections built in. People must be engaged as partners rather than coerced.

Leaders need to connect to people's core values, the reasons their hearts got them involved in mental health in the first place. Then they need to connect those core values to the larger recovery transformation mission and find a place for everyone and their hearts.

Leaders will have to attend to the interfaces between each of the five levels – consumers and families, staff, programs and leaders, system administrators and auditors, and community – so there is

collaboration rather than power struggles between them. This process will require a lot of dedicated leaders.

### Personal Afterward

I'm proud to be the first full-time psychiatrist hired by the National Mental Health Association of Greater Los Angeles (MHA). One of the things I like about MHA is the logo of the MHA bell on our business cards and stationery.

The story of the MHA bell goes something like this. In World War II there was a set of conscientious objectors, mostly Quakers, who were assigned to work in mental asylums instead of fight in the war. The combination of decrepit, inhumane institutions and these highly principled workers proved a volatile one. They engaged in substantial advocacy efforts.

Perhaps the most symbolically powerful of these efforts was to create the MHA bell. They collected up the iron chains and cuffs that had been used to bind patients to the beds and walls. The chains and cuffs were brought by train from all over the country and melted down into an enormous bell. On it is inscribed, "Cast from shackles which bound them, this bell shall ring out hope for the mentally ill and victory over mental illness."

When I've retold this story I've always visualized the moment of triumphantly striking the bell. However, for that moment to be possible there must have been many other moments in the months that preceded it, where some staff literally unchained some patient. The staff must have hesitated in fear, wondering about being attacked. He must have reached out as though untying a wild animal, hoping and trusting a little that he wouldn't be hurt.

And on the other side, there must have been a patient, filled with anger. Although sorely tempted to lash out against the captor who led him by a leash to the toilet the day before, the patient decided not to attack. He had to hope and trust a little that the staff was really going to help this time as he accepted the staff's outstretched hand.

That moment, on both sides, is the moment in which healing and recovery are possible. That is the moment when fear and mistrust are put aside enough to reach out honestly and caringly to each other. That is the moment that makes emotional connectedness possible. That is the moment that makes triumphant bell ringing possible.

If we are to be honest, each of us face that moment every day. We can't respond, "The rules force us to keep people chained," "It's too risky," or "I've been hurt too many times before." We must courageously reach out to each other every day.