

*There's a big difference between creating a recovery based program, even a relatively comprehensive one like the Village, and creating a recovery based system. Even the President's New Freedom Commission Report relied on citing a number of examples of programs (including the AB2034 program that the Village is a part of) not of systems. Systems are much harder to truly describe or define. By their nature, they consist of a variety of interconnected "rules" of various kinds, not of a variety of people or programs. These rules exist on many levels. Some "rules" we're painfully aware of and some are so embedded in our culture that we assume they're just the way things have to be. A successful program can be created by adapting to the "rules" around it. A successful system must deliberately create successful "rules."*

*This paper was my first effort to move personal transformation, practice transformation, or even program transformation to system transformation. I began by rewriting the "rules."*

## **A Wish List of Broken Rules**

**(2004)**

Last year the President's Commission on Mental Health boldly called for a transformation of the entire mental health system, declaring we were beyond repair. I have participated in efforts, on a variety of levels, to begin this transformation. In general, people are highly responsive to adding resources and programs to what they presently do. In general, people are highly resistant to destroying, or even substantially changing, what they presently do. The old saying, "I'm in favor of progress, it's change I'm uncomfortable with" has popped up several times. Yet transformation does require substantial destruction. Not only do the resources for creating the new have to come from the old (although California is making a strong effort through the initiative process to create substantial new resources to promote this effort), but also on a personal level, every one of us has to stop doing something familiar to start doing something new.

The Village began with a training film championing this process of change and we use it in all our onsite immersion trainings. In the film Ernie from Sesame Street has to put down his rubber ducky to be able to play the saxophone. He needs a lot of persuasion and has a hard time letting go, but eventually he makes it.

Last year a pair of anthropologists from UCLA studied the Village to try to figure out why we're so consistently successful and why we're so difficult to replicate. Their conclusion was both startling and somewhat disturbing. They concluded that the Village worked because we "treated people like people." They described how, far from a normal process, "treating people like people" required an enormous will to fight powerful forces working against it. Many of these forces, they felt are imbedded in our professions and our treatment culture, in the hegemony of mental health. They detailed a number of the Village's strengths: A powerful rehabilitation/recovery vision and practice, a protective parent organization MHA-LA, good internal communication, a flat organizational structure, a high ability to adapt and change while preserving our values, etc. These traits have given us the strength to maintain "treating people like people" thus far in spite of constant regressive pressure from the system itself.

We can't expect every program to have the resources and strengths of the Village needed to fight the system. If we are to spread recovery, the President's Commission is correct. The system itself must be transformed. The system is maintained through a network of "rules". We must reexamine these "rules" and willfully destroy those that prevent recovery programs from developing. Unfortunately, these "rules" exist on a number of levels and come from several sources making destructive efforts more difficult.

Here's my "Wish List of Broken Rules"

- 1) Funding must not support only clinical services. Clinical services in isolation do not work very often. Most supports (e.g. housing, employment, and financial) can only be used effectively by people with severe mental illness with lots of help. This help needs to be integrated into the clinical services. The dominant funding source for public mental health services is Medicaid (MediCal in California). This is a medical insurance plan that only pays for "medically necessary" services. It is also a diagnosis based plan. Medicaid often says that they're not forbidding us from providing support services; they just don't think their medical insurance plan should pay for them. Breaking the rule that Medicaid is just a medical insurance plan that would address this problem. The rehabilitation option and some waivers have begun to move us in this direction.

The problem is compounded, however, because when other funds are available (e.g. county or state general funds, shelter-plus housing support funds) the usual "rule" is that these funds must be used to leverage additional Medicaid funds to the maximum degree possible. This "rule" forces us to use less-restricted funds in accordance with Medicaid rules. Even though the total dollar available may be less, we need to use other funds to supplement Medicaid not just to leverage it.

- 2) Programming must not be limited to clinical services. Obviously this would be easier if funding rules were changed, but there are more rules to change than that: Goals should reflect quality of life outcomes not diagnosis based symptom reduction. Outcomes that reflect quality of life (e.g. housing, employment, incarceration, education, and income) need to be collected instead of symptom level outcomes (or no outcomes at all). The "it's not my job" rule needs to be broken. Money management/payee, supportive housing, jail diversion, employment, community integration, etc. are our job. The "rule" that clinical services, especially emergency and hospital services, need to be provided first and then, as a lower priority, provide support services needs to be broken as well. (This rule is fortified by medical liability "rules" whereby people are sued for not providing "appropriate" emergency care, but not sued for not providing "appropriate" support.)
- 3) Staffing must not be limited to clinical professional staff. Assigning clinical professional staff to do needed quality of life, support services creates resistance and resentment. Social workers aren't payees, psychiatrists aren't job developers, and psychologists aren't self-help leaders. Only a portion of an integrated service agency's staff should be clinical professionals. It should include non-professional case managers, consumers, family members, employment staff, community integration staff, substance abuse specialists, health care nurses, etc. Beyond that,

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creating collaborative relationships with lots of different people with mental illnesses requires teams to be multiexperiential, not just multidisciplinary.

- 4) Program accountability based on counting units of service documented in patient's charts must be replaced by outcome accountability. Programs spend enormous amount of resources (estimated about 30% of total funds) to be accountable and auditable in the present systems, virtually none of which are either useful clinically or reflect patient outcomes. These "rules" are too costly not to be destroyed and replaced with outcome accountability.
- 5) Risk management and liability avoidance must not rely on risk avoidance. While it is true that it's hard to be sued for not giving someone an opportunity to grow and recover, that's not the only way to avoid suits, and it is the way most destructive to recovery programs. Risks are to be prepared for, supported, and learned from, not just avoided. Conscientious preparation and ongoing supportive relationships can be our protection from tragedies and suits.
- 6) Multiple roles for service providers must not be forbidden. A holistic model like recovery requires staff be holistic. For a person to embrace other roles besides helpless, cared for, chronic mental patient, staff needs to embrace other roles besides helping, caretaking, mental health professional. We can best be effective promoters of recovery by not restricting ourselves. A psychiatrist can help as a customer at a clubhouse restaurant, a fellow sports fan, a community neighborhood cleanup volunteer, a wedding guest, etc. Self-disclosure, when not intended to get help for ourselves, is usually relationship building and recovery promoting.
- 7) Staff - client "boundaries" must not be strictly maintained. Breaking down the "us vs. them" distinction is essential to promoting recovery and fighting stigma. Strict boundaries reinforce that distinction. With lower boundaries, ethics become more important and the responsibility of the entire team. The rules against exploiting patients, having sex with patients, assaulting and abusing patients should not be broken. But, we can't promote recovery while preserving the enormous thicket of "rules" that have proliferated from these few essentials. Hugging, sharing feelings, accepting gifts, making home visits, giving people rides in our cars, eating together, sharing bathrooms, attending social events together, talking outside of "therapy hours", etc. all may be problematic in specific situations, but shouldn't be globally forbidden. Those are often the very actions that people find the most caring and helpful. The most productive breaking of both the "role rules" and the "boundary rules" is the hiring of numerous people with severe mental illnesses as program staff.
- 8) Protecting blanket confidentiality must be replaced with protecting patient choice. The underlying purpose of confidentiality was not to promote secrecy. Often sharing with other people can be very healing, generate emotional and practical support, decrease stigma, increase community integration, and decrease isolation, hopelessness and suicidality. The purpose of confidentiality was to protect against unconsented and unchosen sharing. From this point of view staff choosing not to share without asking the patient is just as much a problem as sharing without asking.

- 9) Protecting staff by restricting patients to small guarded areas must be replaced by protecting everyone together. Isolating, coercing, and disempowering people leads them to become more frustrated and dangerous, both to staff and to each other. Including, collaborating with, and empowering people leads to shared responsibility for protecting each other, “a community watch”. We can’t effectively urge our communities to accept mentally ill people while we quarantine them in our own programs.
- 10) Separating mental health and substance abuse must be replaced with integration. The overlap is so enormous there is barely any rationale for specialized services that exclude one or the other. Even collaboration between specialty services is unlikely to produce good treatment. Full integration of patients, staff, and programs is the most effective approach. Unfortunately, the “rules” against this integration exist on numerous levels from funding, to staff comfort and expertise, to social stigma and political leverage, to moral and emotional reactions.
- 11) Rationing services by diagnosis must be replaced with rationing by disability and life impact. The present system has acceptable “severe mental illnesses” and unacceptable, presumed less severe illnesses. In practice, however, people may become severely disabled and their lives may be destroyed by a wide variety of conditions. Both social responsibility and individual humanity dictate that we don’t turn away disabled, destroyed people just because they have the wrong diagnosis. This “diagnostic rationing rule” leads to patients lying, incorrect diagnosis and treatments, and wide spread hypocrisy, all unnecessarily. Rationing care is an unfortunate reality, but rationing by diagnosis isn’t the right rule to use.

I believe a transformed, effective, recovery based mental health system will have to destroy all these rules before these rules destroy the programs and the people trying to change.

*I’ve tried to work more with system change since I wrote this piece (as you’ll see from some of the pieces that follow) and have become more convinced than ever that if we are to have long lasting system transformation we will need to transform the infrastructure of our “rules.” My wish list really hasn’t change much, but I’ve become a little more modest in my goals. Now I’m trying to focus on two things:*

*1) There must be consumer, family, and line staff input into the rules. We all hate writing rules, so we abdicate the task to administrators who may or may not have ever been involved in direct service and who are likely to have only a limited awareness of what our lives are like. We need bottom up as well as top down communication. Too often an administrative decision intended to assist with one issue creates a number of unintended problems in other areas that weren’t anticipated and perhaps could’ve been had there been input from the trenches. It’s not enough for us to complain that the administrators never come down to us to see what’s really going on. We have to take the responsibility to go up to them to actively participate, even if it means taking time out of our busy schedules to attend “stupid meetings,” even if we aren’t really welcome, and even if they tend to “shoot the messenger” when we tell them how*

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*their decisions actually played out. The “rules” are made in those ‘stupid meetings,’ so if we want better rules we have to show up.*

*2) It’s unrealistic to expect recovery needs to determine every rule. However, it is realistic for the impact on recovery needs to be considered for every rule. Certainly, there are other important values in rule writing – for example, revenue generation, cost control, limiting legal and financial liability, employee work conditions, safety, community and political support, publicity, etc. – but recovery impact needs to be at the table when choices are made. Too often at present it isn’t even a factor.*