

The Recovery Model

Handouts and Reference Materials By Mark Ragins, MD

I have enclosed in this packet several short documents that highlight various aspects of recovery based transformation:

- 1) The Four Stages of Recovery
- 2) Person Centered vs. Illness Centered
- 3) We Treat Chronic Illnesses, Don't We?
- 4) Milestones of Recovery Scale

If you would like more detail, I have written several longer documents that contain almost all of the details and stories in my presentations. You can find these on the MHA Village website at www.village-isa.org under the dessert section of the menu labeled Village Writings...

- 1) A Road to Recovery
- 2) A Guide to Mental Health Transformation on a Personal Level
- 3) Proposition 63 Begins: The Mental Health Services Act Implementation Toolbox

As you will see, the website contains my writings over a number of years. I try to add new articles as I write them. For more information on the MHA Village, peruse the website! You can also check out www.mhala.org.

I can be reached through MHA's Training and Consultation Department if you contact Sara Ford at (562) 437-6717 x314 or sford@mhala.org.

The MHA Village provides trainings and consultations based on psychosocial rehabilitation. Trainings focus on the recovery model and include topics such as employment, community integration, psychiatric care, dual diagnosis, housing, intensive service coordination, transition age youth, outcomes, recovery-oriented leadership as well as a menu of consultation services focusing on transformation based on the Mental Health Services Act.

*MHA Village Integrated Service Agency
a program of the National Mental Health Association of Greater Los Angeles
456 Elm Avenue
Long Beach, CA 90802
phone (562) 437-6717 fax (562) 436-1928*

The Four Stages of Recovery

By Mark Ragins, MD

Recovery is the normal adaptational process that follows destruction just like grief is the normal adaptational process that follows loss. Often the two processes supplement each other. The fluid stages of grief – denial, anger, bargaining, depression and acceptance – were first described in the complex context of death and dying, but have been found to be highly generalizable to other serious losses. Recovery has been described in a number of fields, our own work is in the complex context of serious mental illnesses, but any successful description ought to be highly generalizable to other serious destructions. Our present description has four fluid stages – hope, empowerment, self-responsibility, and having a meaningful role in life.

Hope

In the blackest times of despair what's needed first is hope as a light at the end of the tunnel, some idea that things can get better, that life will be more than the present destruction. Without hope there's no real possibility of positive action. To be truly motivating, however, hope has to be more than just an ideal. It has to take form as an actual image of how things could be if they were to improve. It's not so much that people will attain precisely the vision they create, since realistically most outcomes are products of chance and opportunity more than careful planning. But it does seem essential to have some clear image, if people are to make difficult changes and take positive steps.

Empowerment

To move forward, people need to have a sense of their own capability, their own power. Their hope needs to be focused on things they can do rather than new cures or fixes someone else will discover or give to them. It is often needed for someone else to believe in them before they're strong enough to believe in themselves and to start focusing on their strengths instead of their losses. It also often takes some actual experience of success to really believe one can be successful. Waiting until someone is ready to move on can often be stagnating and disempowering, because "readiness" often occurs only in retrospect after something has been done successfully.

Self-Responsibility

At some point most people who recover realize that no one else can do it for them, that they have to take charge of their recoveries. People can, and often need, to be supported in their efforts to recover, but they can't be caretaken or protected into recovery. Taking one's own risks, setting one's own goals and path, and learning one's own lessons are essential parts of recovery. The appeals of dependency and being taken care of can derail a recovery as can being too frightened or traumatized to take risks.

Meaningful Role in Life

Ultimately to recover one must achieve some meaningful role apart from the destruction. Becoming a destruction victim is not a recovered role, and frankly, neither is destruction survivor. After achieving increased hopefulness, inner strength and self responsibility,

these traits are applied to meaningful roles apart from the destruction. The blackness of destruction that once seemed to swallow the person whole recedes in importance as the person's other meanings emerge. Connectedness to other people, belonging, and feeling accepted, that may have for awhile only been possible with others who had experienced related destructions, within families, or with compassionate helpers becomes possible in a variety of contexts. The isolation and aloneness the destruction imposed is increasingly broken and life re-entered.

Put together as a coherent series of stages these descriptions can provide a roadmap, albeit a fluid one, of the process of recovery generally and can be applied specifically to our work in helping people recover from the destruction of serious mental illness.

The stages of grief have sometimes been applied to medical oncology service by including a specialized counselor or social worker. Sometimes a special hospice service is provided separately from the medical oncology service and "appropriate" people are referred to it when they are ready. Rarely an entire oncology service is built upon these stages and experiential values and it infuses the entire service. The stages of recovery have sometimes been applied to a psychiatric mental health service by including a specialized rehabilitation worker or consumer advocate. Sometimes a special rehabilitative or clubhouse service is provided separately from the psychiatric mental health service and "appropriate" people are referred to it when they are ready. Rarely an entire mental health service is built upon these stages and experiential values and it infuses the entire service. The Village Integrated Services Agency is an entire comprehensive, integrated mental health service built upon rehabilitation/recovery principles and values.

Now in our tenth year of proven success with a variety of people with serious mental illnesses, including homeless, jailed, "high-utilizing", state hospital, and conserved people, we have become a powerful model of a recovery based program. We have been involved in numerous efforts to spread our principles and practice, working towards widespread system change.

Person Centered vs. Illness Centered

By Mark Ragins, MD

I've been doing a lot of workshops lately trying to help people really "get" recovery. I'm beginning to think that a crucial step to open up a clear vision of recovery is to move from an illness centered perspective to a person centered perspective.

Let me try to explain with an analogy: Before Copernicus came along we believed that the earth was at the center of the universe and that everything else moved around it. Although this made sense to everyone, it did make it difficult to describe the orbits of the other planets, the sun, and the stars as we observed them moving around the earth in complex, idiosyncratic paths. Copernicus figured out that although the earth is a very important place, it isn't actually the center of the universe or even our solar system. The earth is one of a number of planets that revolve around the sun. It turned out the orbits were simple ellipses explainable by gravity.

Our mental health system at present is almost entirely illness centered. We act as though we believe that illnesses are at the center of the universe and that everything revolves around them. We need a great deal of complex, idiosyncratic explanations to make sense of people's lives from this perspective: Housing is in treatment settings, friends are social support networks to reduce the risk of relapse, employment is therapeutic activity, and families are given psychoeducation so they can be extensions of treatment professionals. If we drive someone to a job interview we write a MediCal note stating that we did in vivo anxiety reduction and social skills training for a schizophrenic who has barriers of paranoia and interpersonal anxiety in order to get him some employment as a therapeutic activity in order to decrease his symptoms and reduce the risk of hospitalization. That all may be true but it's a pretty convoluted, pre-Copernican orbit.

We can change our perspective. We can figure out that although illnesses are very important, they aren't actually at the center of life. People are. It turns out that the orbits are relatively simple from this person centered perspective. People live in homes; have friends, jobs, families, and illnesses. When we drive someone to a job interview we're trying to help them get a job.

Our illness centered perspective pervades everything we do. For example, when someone first comes to us in need of help with their problems the first thing we do is to define their problems as symptoms of an Axis I Major Mental Illness. If we can't do this, they're not eligible for services. We can't get paid. They have to go away even if there's no other help available. If we can identify their illness, but they can't, they are lacking insight and we need to assess them for dangerousness, suicidality and grave disability. If they have any of those things we can lock them up. If not, there's nothing we can do. We rarely shift to a person centered perspective to find other ways to be helpful.

If we both agree they have an illness, we can try to help them within our illness centered perspective. We can give them treatment for their illness and if we can relieve all their

symptoms, they shouldn't have any more problems, since their problems were all symptoms in the first place. If, as is far more common, we are unable to relieve their symptoms, even with multiple medications and lengthy therapy, we can get them other social support services as long as we can use their ongoing illness to justify their needs. Labeled with the correct diagnosis, they can get Social Security income, Shelter Plus housing subsidies, vocational rehabilitation, disabled students' support, etc.

When someone first gets a serious illness it can feel like it swallows them up. It's hard to hold on to their remaining strengths and keep hope alive. Our illness centered responses, in effect, agree with this alarming feeling. We can clearly see that the illness has indeed swallowed them up. We took a careful history of their illness that documented it. They are now officially a schizophrenic or a manic depressive. But they shouldn't lose hope just because we don't see their strengths either. They've come to the right place. We'll be the strong ones for them now. Hope rapidly becomes entirely coupled to our ability to successfully treat their illnesses. They can try to keep hoping we'll be able to cure them and that then they'll be fine again. Unfortunately, along the way we may neglect and lose all the other things that used to give them hope before they became patients like family, loved ones, their own strengths, God, perseverance, resilience, pets, understanding, compassion, or love. With illnesses at the center of life instead of people, treatment is the only visible wellspring of hope.

I was taught in medical school the distinctly illness centered idea that the foundation of a good treatment is a good diagnosis. I no longer agree. It seems to me that the foundation of a good treatment is a good relationship with the person – a distinctly person centered idea. Think about it. If I have a good diagnosis, but no relationship it's not really very likely that much will happen. On the other hand, if I have a good relationship, but the wrong diagnosis, I'm a pretty smart guy, I'll figure it out, and, more to the point, they might trust me enough to tell me the truth about their illiteracy, sexual molestation, drug abuse, lack of medication taking, abusive spouse, or whatever it was that they were hiding that confused me in the first place. (Of course if I was firmly illness centered enough, I wouldn't see any problem as a lack of relationship. Instead I'd see, as a recent analyst of the CATIE drug study did, that "patient-initiated drug discontinuation appears to be a core illness behavior from schizophrenia onset to chronic illness.")

The reason it's important to change from an illness centered perspective to a person centered perspective to "get" recovery is because illnesses don't recover, people do. Illnesses can be cured, put into remission, stabilized, or controlled, but they don't recover. The person with the illness recovers when they rebuild their lives from the destruction caused by the illness. There's no need for recovery if there's no destruction from the illness. Illness centered treatment is sufficient. Unfortunately, most people with serious mental illnesses do have destruction in their lives and need person centered recovery services. The process of recovery is the same whether they're recovering from an illness or from any other serious destruction, like a rape or the death of a loved one, or the trauma of an abusive childhood, the lack of a family, or going to war. People can recover functions - as in the ability to read, to sleep restfully, to work, to have coherent conversations, to make love, to raise children, to drive a car, etc. People can recover

external things – as in an apartment, a job, friends, playing in a band, a spouse, a car, family relationships, stereo, TV, educational programs, etc. And people can recover internal states – as in feeling good about oneself, satisfaction, self confidence, spiritual peace, self-identity other than mentally ill, self-responsibility, etc. But when all is said and done, it still remains that illnesses don't recover, people do. That's why we can't even see recovery from an illness centered perspective. It simply doesn't exist. We must switch to a person centered perspective for recovery to emerge.

Here's an example: Imagine a spectacular football player. He runs with amazing grace and abandon. He cuts sharply. He's fearless. He finds the holes seemingly by instinct. And now imagine that a hard tackle twists his knee and severely injures it. But he gets great medical care. His arthroscopic surgery is a success. He's very motivated so he does months of strenuous rehabilitation, and as a result his knee is completely healed. Tests show that it's just as strong and flexible and mobile as ever. But, when he gets back on the field somehow he's never the same. He doesn't move the same way. He's been changed by the injury. Even though he's no longer injured, he's still subtly crippled. More treatment simply won't help, unless we switch to a person centered approach. We have a large number of people with serious mental illnesses who, even if we gave them pills tomorrow that relieved all their symptoms would still be severely "crippled." As a matter of fact, we have lots of people who we've already given them those pills who are still on our caseloads crippled. And we keep giving them more illness centered treatment.

Don't misunderstand me. I'm not against treating illnesses. It's much easier to avoid being crippled if there's effective treatment and rehabilitation. But I am against waiting to begin person centered recovery services until after the illness centered treatments are successful. Recovery should be our principal concern from the beginning. After all, isn't that football player thinking about how he's going to return to the field from the moment he's injured? "Meeting people where they're at" usually means beginning with recovery.

By contrast, the beginnings of public mental health treatment are usually far removed from recovery. I've heard that half of all people in the public mental health system enter involuntarily. These people are forcibly restrained by police or ambulance personnel and brought to crowded, frightening psychiatric emergency rooms, and rapidly sedated often with forced injections "losing" their mind still further. Too often, we're inadvertently adding more trauma and destruction to be coped with later and dramatically reducing their sense of hopefulness, self confidence, collaboration, and self determination - the keys to their recovery. Even if people begin voluntarily in a clinic, they're likely to have to begin with long waits and extensive intake processing that focuses on system needs and diagnostic based treatment plans that may be experienced as impersonal processing not really responding to their needs. Most don't return.

Here's my view of person centered recovery based services from beginning to end: The first priority is to establish a relationship. If people don't return, even the best assessment and treatment plan is a waste of time and paper. We should have a variety of outreach and engagement offerings to welcome people, whether they come voluntarily or

involuntarily, that precede assessment. These offerings should be based on helping to meet the person's goals directly. For example we might help by actually listening to make someone feel better. We might help them straighten things out with their family or boyfriend. We might give them instructions how to get a two week hotel voucher from the welfare office, or advocate for them to get their SSI check restarted. We might call family to get money sent for a ticket home. We might give them a cigarette and a quiet place to think. We might give them a lunch or a day labor job to make \$20. Or we might even give them an explanation for what is wrong with them so they're less confused and more hopeful. After we've been helpful, perhaps a number of times, the person may be engaged enough with us to form a collaborative service relationship.

The goal of our service is not to treat illnesses, but to help people with serious mental illnesses have better lives. For example, when we give someone medication it's not to reduce voices; it's to help them get a girlfriend or keep their job. We focus not on illness based outcomes, like symptom relief, but on quality of life outcomes, like improved housing, employment, education, finances, health care, social life, and families, while avoiding legal problems, drug abuse problems, hospitalization, and homelessness. The goals are socially valued, but individually determined, based on each person's choices. Services, including, but not limited to, treatment and rehabilitation, are goal driven, not symptom driven.

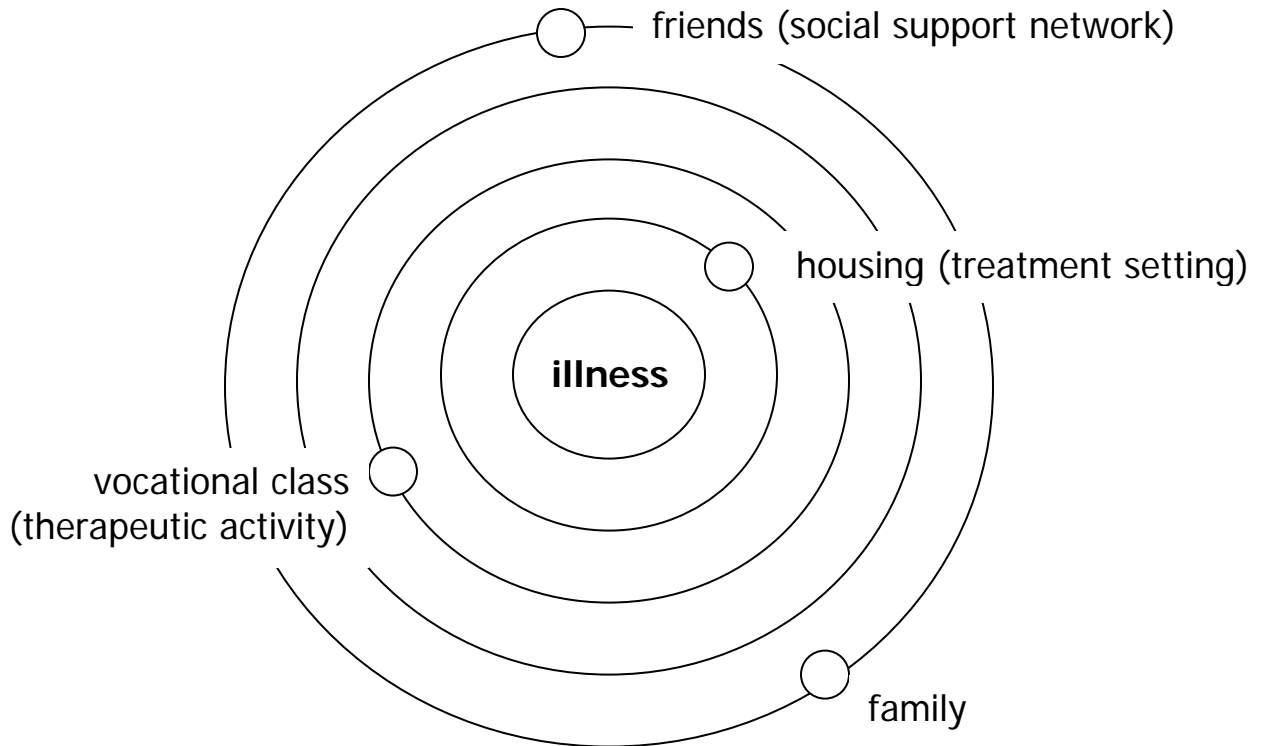
Throughout, a focus on the relationship is primary. SAMHSA's new recovery consensus statement includes following the person's self direction, being empowering, strengths based, respectful, responsibility building, and hopeful. These are all characteristics of service relationships that build recovery. Sometimes we'll give up ground on the illness treatment or rehabilitation if it means gaining ground on the person moving towards a recovery relationship with us.

The goal throughout is to help the person attain recovery. We guide them through the process of building hope, empowerment, self-responsibility and attaining meaningful roles in life. We don't leave recovery to chance, hoping that it will result from our treatment and rehabilitation efforts. We intentionally use treatment and rehabilitation as tools to promote recovery. We chose techniques that emphasize growth, building skills and natural supports, learning from successes and failures, and internalizing recovery gains to enhance resilience and wellness, rather than emphasizing stability, caretaking, risk reduction, and treatment compliance. Recovery is inside of them, not us.

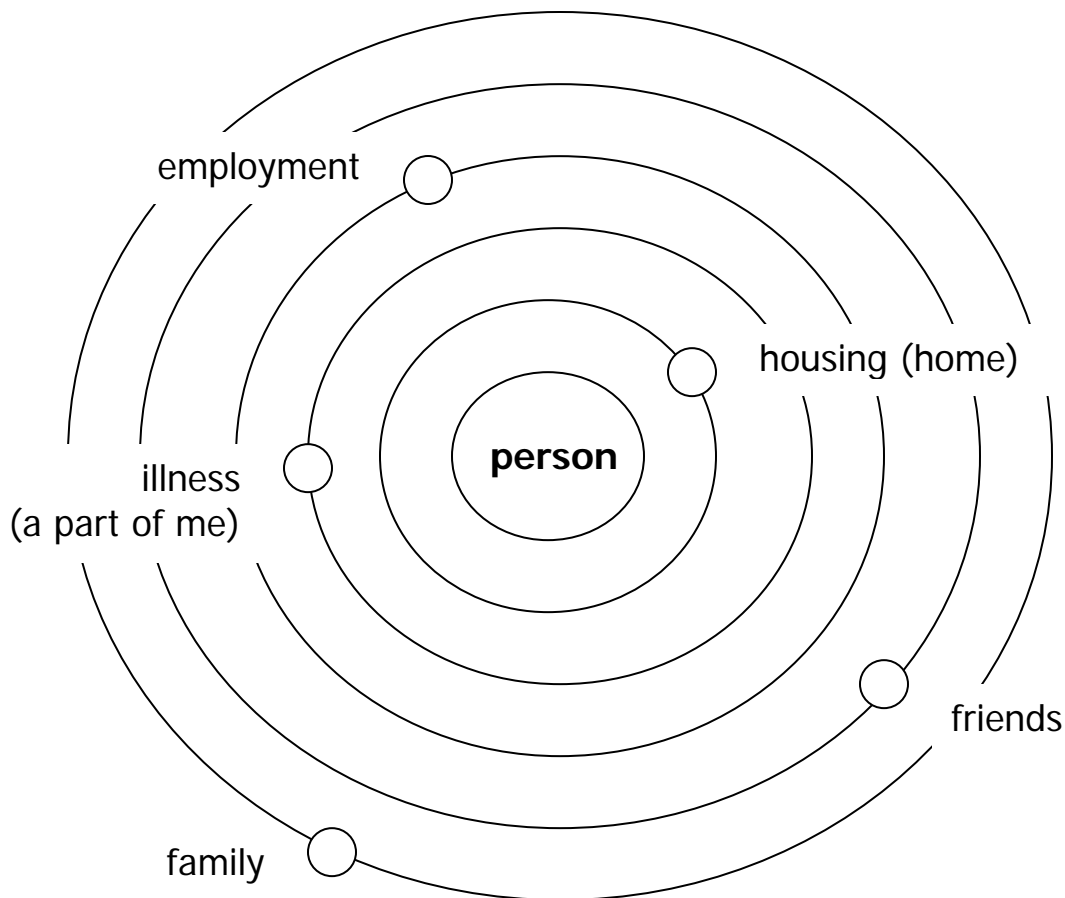
All recovery based services are transitional, though usually not time limited. The person moves on as they grow and change, not as their illness responds to treatment. They graduate and leave the system, when they are able to manage their lives, including their illness if it's still there, not when they are cured.

When all is said and done, the recovery process and what we need to do to promote it is much clearer from a person centered perspective than from an illness centered perspective.

illness centered



person centered



PERSON CENTERED	ILLNESS CENTERED
The relationship is the foundation	The diagnosis is the foundation
Begin with welcoming – outreach and engagement	Begin with illness assessment
Services are based on personal suffering and help needed	Services are based on diagnosis and treatment needed
Services work towards quality of life goals	Services work towards illness reduction goals
Treatment and rehabilitation are goal driven	Treatment is symptom driven and rehabilitation is disability driven
Personal recovery is central from beginning to end	Recovery from the illness sometimes results after the illness and then the disability are taken care of
Track personal progress towards recovery	Track illness progress towards symptom reduction and cure
Use techniques that promote personal growth and self responsibility	Use techniques that promote illness control and reduction of risk of damage from the illness
Services end when the person manages their own life and attains meaningful roles	Services end when the illness is cured
The relationship may change and grow throughout and continue even after services end	The relationship only exists to treat the illness and must be carefully restricted throughout keeping it professional

We Treat Chronic Illnesses, Don't We?

By Mark Ragins, MD

(How dare I include in the title the politically incorrect “chronic illnesses”? Because this paper is not designed to reach out to politically correct recovery champions and consumer advocates. I've written plenty of other stuff for you. This paper is designed to engage our professional staff who, like me, were trained, in long, expensive, professional programs that taught us to help people by treating their illnesses. We're the people you turn to in an emergency, who shoulder the legal and clinical responsibilities in our system, who treat people who need it even if it means coercing them. A successful system, including a recovery based system, must include us. I'm “meeting them where they're at” and trying to bridge the gap between us so we can become collaborative coworkers.)

When the various medical professions as we know them and the “medical model” emerged about a century ago the vast majority of patients had acute illnesses, mostly infections and injuries. The average life span was about 45 years. As we became more effective treating those illnesses the prestige of medicine grew and people started living long enough to get chronic illnesses. At the present time the vast majority of medical patients have chronic illnesses, but medical practice hasn't been transformed to meet patients' changing needs. Psychiatry, seeking similar prestige and funding levels, has increasingly sought to model our practice on the acute illness medical model used by our medical colleagues. Public psychiatry patients almost all have chronic illnesses, both because we target our efforts on people with serious, persistent mental illnesses and because there is so much stigma attached to mental illnesses that people rarely seek help until after they've been struggling on their own unsuccessfully for a long time. There are significant differences between how acute illnesses should be treated and how chronic illnesses should be treated that I will discuss in this paper. I believe that public psychiatry is not likely to meet our patients' needs more effectively while adhering to an acute illness model instead of a chronic illness model.

Chronic illnesses differ from acute illnesses in several important ways:

- 1) With acute illnesses it's reasonable to withdraw from life while being treated, whereas, with chronic illnesses the patient should try to maintain their “normal” life while being treated.
- 2) The ongoing symptoms of chronic illnesses often make it hard to maintain a “normal” life, necessitating rehabilitation to increase function, personal adaptations to cope, and community adaptation to maintain access to life.
- 3) Chronic illness more often than acute illnesses effect people's self identity.
- 4) Hope is more difficult to maintain for both patients and professionals with chronic illnesses because the symptoms resist treatment and helplessness settles in.
- 5) Recovery from acute illnesses usually results from symptom relief, whereas, recovery from chronic illnesses usually results from being able to maintain wellness and responsibility for self-

care and being able to replace professional supports with natural supports while rebuilding a meaningful life.

These differences have important treatment implications that have never been adequately addressed by our professions, our education, our helping roles, or our funding system. The premise of this paper is that if we seriously address the care of chronic illnesses we will arrive at almost all of the “recovery model” without ever really leaving the “medical model.”

The treatment for most acute illnesses can be done to the patient, whereas, the treatment for most chronic illnesses must be collaborative.

Patients with acute illnesses can literally turn their lives over to professionals to be treated, even living in a controlled hospital environment for awhile if needed, confident they will retake control over their lives once they are well again. All the patient is expected to do is “follow doctor’s orders.”

Treating patients with chronic illnesses the same way, whether they have asthma, diabetes, sickle cell anemia, AIDS, schizophrenia, or alcoholism is rarely successful. Long term “treatment compliance” is amazingly low with all chronic conditions. We simply can’t expect people to put their lives on hold indefinitely or stay living in hospitals for long periods waiting for treatment to work. They’ll choose to drop out of treatment rather than drop out of life. Acute hospitalizations tend to become “revolving door” because the condition continues long after the “stabilization” achieved in the hospital is long gone.

Instead, the patient must make chronic changes to impact their chronic illness while going on with their lives. The changes they need to make fall into two categories: Self-help and wellness. Self-help involves actively engaging in the treatment process, learning about your illness and how to deal with symptoms when they occur either on your own or with professional assistance. Wellness involves knowing what’s needed to prevent symptoms from occurring and how to keep symptoms from disturbing your overall sense of wellbeing and ability to go on with your life. Both include recognizing your warning signs, exacerbation signs, and crisis signs, knowing what to do about each, and having the self confidence and self responsibility to make the necessary decisions and take action.

Neither self-help nor wellness can be achieved by relying on a “follow doctor’s orders” model. A more empowering, collaborative model is needed.

The treatment for chronic illnesses requires more teaching and usage of self help techniques than the treatment of acute illnesses.

Teaching people about their condition and how to help themselves can take a lot of time, but if we don’t take the time to do it we’ll find ourselves taking care of them in the same situation over and over again (Think teaching to fish instead of giving a fish). We often find ourselves taking care of someone over and over again in the hospital without them really learning what changes they’ll have to make in their life to stop being hospitalized. Similarly, we work with people who stop taking their medications over and over again without really getting through to them to stay

on their pills. Without really realizing it, we're acting as if every hospitalization and every relapse is basically a new acute illness. We don't often help patients learn from their past.

Many people with chronic mental illnesses are not appealing students. Some were in special education classes or did poorly in school. Some have poor concentration or are irrational. Some are wrapped up in their own worlds, slowed down by depression, or confused by anxiety or mania. Some people even reported that people with schizophrenia have a "failure of historicity" meaning they can't learn from their pasts. One look at UCLA's skill training modules with their pervasive repetitiveness can give us some idea how hard teaching them can be. It's not impossible, but sometimes it's a lot of work.

The most overwhelming obstacle to teaching many people with chronic mental illnesses is that they "lack insight." They refuse to agree with us that they have an illness at all, so how can they learn about their illness and how to help themselves? There is a way around this blockage. Remember when they did the meta-studies of psychotherapy? It turned out that for a therapy to succeed, it didn't have to have the "right" explanation for the person's pathology. We could succeed with psychoanalytic explanations, behavioral explanations, interpersonal explanations, or a host of others so long as it was a "shared" explanation – one both therapist and client could agree to base their work on.

Our present dominant explanation, that a neurochemical imbalance causes most chronic mental illnesses, suffers from an impressive lack of "face validity" or "intuitive appeal." It just doesn't feel true to most people. It's a hard explanation for people to share with us. We can widen the number of people we can teach if we have at our disposal a wide array of plausible explanations we can choose between depending on which one our client is most likely to believe. After all, most people with chronic mental illnesses think something is wrong. They just don't think it's a neurochemical mental illness. Just like they're sure they're not crazy.

Would you be willing to teach someone that they're drowning in the same deep waters that Saints swim in and need to take medications and keep themselves grounded because they aren't prepared to use their spiritual gifts? Would you be willing to teach someone people to go on a "thought diet" like John Nash did in "A Beautiful Mind" to return to reality from the seductions of his unfettered thoughts? Would you be willing to teach someone to take medications and avoid using speed to strengthen his brain to fight off rays from a machine in outer space? Would you be willing to teach someone to create a "mother angel" to care for the "baby angels" whose cries have been keeping her awake for several years since her children were taken away from her? It makes for strange "informed consents," but I've used all of these "shared explanations" to teach people to take care of themselves who lacked insight.

Another problem with our prevailing neurochemical model is that it offers only limited opportunities for self help. Generally our advice boils down to, "Take your meds and avoid stress." That's barely hopeful and definitely not empowering or engaging.

We have been taught Cognitive Behavioral Therapy, that's proven for both depressive and psychotic conditions, and a variety of relaxation and anxiety reduction techniques, but in actual practice we don't use them much. We claim we're including them in our individualized

supportive therapy instead of using the “manualized” procedures because most of our chronically ill patients just don’t seem to be responsible enough for the “real thing” but, in reality, we’re far more likely to resort to problem solving, care taking, case management, structuring, and making decisions for people than teaching. The overt decision to individualize and include teaching within support is probably correct. The covert decision to abandon teaching probably isn’t correct.

There are a wide variety of other self-help techniques that have evolved out of the consumer movement (for example from the National Empowerment Center). Even though some of these like WRAP (Wellness Recovery Action Plans) have attained national prominence, virtually none of them have been included in professional curriculums or CEU conference trainings because of their non-professional origins. Many of these are more suited to our patients than the professionally created products and easier to use.

On the face of it, it would seem that all of this would require more motivation and participation from the patients, not less. It would seem easier to be dependent on professionals and cooperate with being taken care of than to learn to take care of yourself and work collaboratively with professionals. If we’re already having problems with compliance, why make things worse? Because one of the main reasons patients aren’t compliant is that the treatment doesn’t “work” in the way they expect it to work. They expect to be made well rapidly by the professionals and that doesn’t happen if they have a chronic illness. When that doesn’t happen they often withdraw. The expectations and the nature of the helping relationship need to change from the outset if we’re going to get more collaboration. The patients have to change models too.

The treatment for chronic illnesses, unlike acute illnesses, requires actively engaging the person in their own treatment process.

Attempting to engage people in the ways we’ve been taught, within the structures of our “auditor friendly” systems, who may be impaired by their mental illnesses and may not even believe they have a mental illness has been incredibly frustrating. The most common recommendation to address this problem unfortunately has been to recommend increased coercive powers to make people receive treatment whether they’re engaged or not. That might work for acute illnesses but not for chronic illnesses. Long term engagement is essential for people with chronic illnesses.

There are those who claim that forced treatment can achieve engagement by reducing symptoms and “restoring people to sanity” which will help people regain “insight” and then engage in treatment. While this may occasionally be true, far more often it leads to inadequate engagement and the “need” for further involuntary treatment.

The way out of this dilemma is to achieve engagement with people who are actively symptomatic and “unreachable.” A recovery based system approaches long term engagement very differently than our usual system. Many of their techniques are more effective than our usual ones. Here are some concrete examples:

1) Our system builds treatment on a good diagnosis. Our initial contact is normally an extensive assessment. (Common poor results of this approach are people avoiding us saying, “I don’t want

to have to tell my whole story all over again,” and an incredibly high rate of no shows for second appointments.) A recovery based system builds treatment on a good relationship. Their initial contact, which may be an “outreach” contact, normally focuses on welcoming and engagement incorporating charity, benefits assistance, sharing stories with peers to build hope, lowering boundaries by being “friendly,” finding shared interests and backgrounds, and building emotional connections through extended non-judgmental listening.

2) Our system builds expectations that people will have lower symptoms and feel well as a result of successful treatment. We normally assess symptom relief. (A common poor result of this approach is that people withdraw when they don’t feel better fast.) A recovery based system builds expectations that people will achieve goals they set and rebuild a meaningful life. They normally assess quality of life outcomes (like housing, employment, finances, avoiding legal problems, etc.) that can often be achieved when services are focused on them.

3) Our system hires licensed professionals and expects us to be able to connect with people within professional roles and boundaries thus avoiding any negative personal reactions we may have. (A common result of this approach is that people feel distanced, looked down on, and not really cared about; just part of doing our jobs.) A recovery based system hires lots of people with experiences with mental illnesses many of whom want to “give back” and asks them to use their past experiences to connect with people.

4) Our system tends to prescribe treatments based upon the illness being treated. (A common poor result of this approach is that people feel invisible, like “an interesting case” and disconnected from us.) A recovery based system tends to view treatment as supporting people on their very individual journey of recovery. It highly values their subjective experience of their illness and their search for meaning within a cultural context.

We can reasonably expect as a result of these changes to be asked to work without resorting to coercion with a variety of people we haven’t been well connected to before. Many of them won’t meet our usual criteria for collaborative treatment. They may not believe they have a mental illness. They may abuse drugs. They may not be responsible, missing appointments, not take medications “as ordered,” and not be able to give informed consent. It’s not that we haven’t tried working with some of these people before. It’s that we haven’t been very successful. The recovery model expects us to succeed now. The pressure here is that, unlike in the past when we could blame the patient or the insufficient involuntary treatment laws, now we’ll be held accountable for helping people we may regard as untreatable. An escape hatch is closing.

We’ll be asked to be more flexible and less authoritarian than ever before, more willing to work collaboratively with our patients, more willing to take risks with people working outside the norms and protections of standard medical care, and more willing to rely on nonprofessional and mentally ill colleagues.

The treatment for chronic illnesses requires including its effects on the person’s ability to live successfully.

There's an old study that determined that the correlation between schizophrenia and poverty wasn't due to poverty causing schizophrenia. It was due to schizophrenia causing poverty. They documented that people with chronic mental illnesses tend to experience "downward social drift." Their reasonable conclusion was that the symptoms of mental illness get in the way of making money. We can argue that it's not really the symptoms themselves that are so destructive, but actually stigma, segregation and loss of opportunity, civil rights reductions, treatment effects, institutionalization, etc., but basically we'd all agree that having a chronic mental illness is likely to hinder your life. We just don't like dealing with that reality.

Psychiatrists, psychologists, and nurses tend to push off life problems on social workers. Social workers tend to push them off on case workers and community workers. The entire mental health field tends to push them off on other social service agencies. We all want to stay focused on treating the illnesses themselves. Unfortunately, that just doesn't work very well. Most of our patients with chronic mental illnesses still lead impoverished, heavily restricted lives.

Why should we believe that we could do better if we got more involved? After all, we didn't learn much about housing, employment, education, finances, avoiding jail, or family preservation in school. Because "supported services" (like supported housing, supported employment, supported education) actually work when they're integrated into mental health services. Some are even proven "evidence based practices." It turns out, for example, if a supported employment worker is added to an ACT team many more clients get employed than if they're referred to the local Department of Vocational Rehabilitation. Why? Some would claim it's just a matter of reducing interdepartmental red tape and improving access, but I don't think that gives us enough credit. I think that if we focus on employment we're able to use our understanding of people's illnesses and treatment effects to design effective individualized support plans and I think that if we focus on using our ongoing treatment relationships with people we can help motivate them to implement these plans.

There's a lot of variation in what supports people need and how to motivate them to move forwards. Someone whose concentration is affected by intrusive voices is different from someone who uses marijuana regularly. Someone whose moods are unstable because of manic-depression is different from someone with a borderline personality disorder. Someone who's slowed down from a major depression is different from someone who's on high dosages of sedating medications. Our expertise can help us move from "placement" and generic "training" to more effective individualized supported plans.

The treatment for chronic illnesses often requires including rehabilitation and personal adaptation.

Most of our positive experience with rehabilitation and personal adaptation is, strangely enough, with acute illnesses. For example, many of us have personally experienced dramatic positive effects from a time limited course of physical and/or occupational therapy and a set of crutches helping us to recover from a broken leg. Our experiences of the effectiveness of rehabilitation with chronic illnesses, like muscular dystrophy or chronic heart failure tend to be less compelling.

Perhaps our best outside source of inspiration for effective rehabilitation with chronic illnesses could be special education for learning disabilities: Before special education was mandated, it was routine to consider many children “retarded,” not bother to understand them too carefully, segregate them away from normal children, give up on them as “unteachable,” and take care of them indefinitely. Despite numerous confounding administrative, legal, and fiscal issues, we’ve made substantial progress since then including Individualized Education Plans based on multidisciplinary assessments, “mainstreaming” them into normal classrooms with extra support, and including social and employment skills training to help them become productive adults.

But we don’t really have to look outside mental health for inspiration. There are striking examples of successful rehabilitation within our own fields ranging from UCLA’s early work with “unteachable” patients at Camarillo State Hospital, to Boston University’s inclusion of people with serious mental illnesses in the normal college population using a “chase, get, keep” support model, to Fountain House and numerous other clubhouses helping people who were stuck in patient roles to succeed in a variety of other meaningful roles.

I only really embraced rehabilitation and personal adaptations for chronic mental illnesses (like a Walkman to block out the voices or crocheting a blanket to cope with chronic insomnia or getting a dog to help go outside despite agoraphobia) when I changed my focus from treating illnesses to helping people with chronic illnesses have better lives. We’re not using rehabilitation like the Orthopedists are to help broken legs heal faster. We’re using rehabilitation like the special education people are to help build lives. If you can shift focus from treating illnesses to rebuilding lives – and this is the most important shift that the recovery model requires of us – than you’ll value and learn to use rehabilitation and personal adaptation techniques.

Chronic illnesses affect people’s self-identity more than acute illnesses do.

Very few people become “influenzics” but many people become “epileptics” or “asthmatics” or “schizophrenics.” It takes a chronic illness to internalize truly destructive identities like “cripple” or “retard” or “loony” or “stoner.” A good doctor treating a patient with a chronic illness over the course of many years is likely to become increasingly personal over the years. He remembers your name and not just the medical details of your case. He’s likely to talk about how your life is as much as how your illness is. He gets to know your family. This has the effect of stopping the illness from swallowing you up. The message is, “You may have to come see me because of your illness forever, but that doesn’t mean that’s all there is to your life.” The illness doesn’t have to define who you are even with the professionals treating you. They can relate to you in a friendly way instead of a strictly professional way.

Mental illnesses and substance abuse disorders have a particularly virulent ability to rapidly destroy our self-identity and our public-identity. Even a short live postpartum depression, for example, where a mother had thoughts of killing her infant, is likely to permanently and profoundly alter her view of herself as a good mother. If she tells someone else about her symptoms they’re likely to call DCS and have her child taken away entirely. Even one drug conviction for an adolescent can make them ineligible for federal financial aid to go to college and make them feel like a social reject. Mental illnesses and substance abuse disorders are strikingly “crippling.”

We have quite a number of people for whom even if we gave them a medication or a therapy that made all their symptoms disappear, they would still remain on our caseloads crippled for life. In fact, there are many people for whom we've already given them a medication or therapy that made all their symptoms disappear on our caseloads now.

By contrast, Moral Treatment institutions in the 1800s had striking recovery rates. About two thirds of psychotic people admitted to these small, compassionate, God faring institutions were discharged back home recovered within 6 months. We can't even really imagine results like that with our present treatment programs. Why are things so different now? I think mostly because even when we've "stabilized" people they're not really well again; they're still crippled. The illness (including both positive – like financial benefits - and negative effects) has become an ingrained part of who they are.

Moral Treatment didn't focus on treating illnesses. Most of the staff weren't even professionals. They focused on helping you feel whole again, on helping lost souls find their way back to God again, on building you up so you could make a contribution again. Some would argue that this is a good treatment for mental illnesses, but that's not my point. My point is that when the symptoms go down for whatever reason recovery results much more often if you're self-identity has recovered instead of been crippled. (Many recovered people, like John Nash, report that their symptoms aren't gone. They're just easier to ignore, not so urgent, easier to detach from.)

It's important not to focus on the self-identity effects only after acute treatment has achieved stabilization and the underlying crippling has emerged. We must focus on it throughout our treatment process (even when they're tied down, yelling in the ER, yet still able to remember how we treated them). There are too many ways in which we inadvertently contribute to their crippling throughout our treatment process. I've met many people who say they were devastated when a hospital staff told them they had schizophrenia and would never recover and would have to either live with their parents or in a Board and Care forever. Others have never tried to return to work even when they felt better because their old psychiatrist told them they were permanently disabled, work would be too stressful for them and cause a relapse, and because they didn't want to risk their Social Security benefits. The effects of being tied down, mostly naked with cameras watching you, or being called a "dirt bag" in detox, or being told, "Why don't you just get it over with and really kill yourself next time?" can be lifelong.

We need to incorporate a secularized version of Moral Treatment into our daily practice. Some of this will be accomplished by including paraprofessionals who are particularly compassionate, accepting, and hopeful in our treatment teams. Some of this will be accomplished by consumer advocates and "language police" harassing us to change our stigmatizing and traumatizing habits. Some of it will be accomplished by us becoming more personal and friendly, lowering the professional walls, remembering their names, asking about their lives and not just their illnesses, and getting to know their families.

It all comes back to hope.

The reason the phrase “chronic mental illness” is considered politically incorrect is because it carries the implication of hopelessness (and therefore was replaced by “persistent mental illness” which can be persistently fought). The words, “There’s nothing more I can do for you” can’t be far behind. Indeed about half of all clients in our clinics receive “meds only” – brief doctor visits every month or two for unending refills.

We become very defensive when confronted with our pervasive hopelessness and begin looking around for someone else to blame: It’s the underfunded system’s fault. It’s the paperwork and MediCal. It’s incompetent, senseless, or out of touch administrators. It’s restrictive involuntary treatment laws. It’s “low functioning” patients, unresponsive illnesses, ongoing substance abuse. It’s low quality psychiatrists or lazy county staff who don’t really care about people. It’s codependent, sabotaging, exploitative, or crazy making families. The list goes on and on as we descend into a maelstrom of frustration.

I’m casting blame in another direction, on our acute illness model. If successful recovery is symptom relief and cure and treatment is limited to what we can do to compliant patients we’re likely to become frustrated and hopeless. If, instead, we use a chronic illness model other versions of recovery emerge (including self responsibility, wellness, and rebuilding function, roles, and a meaningful life) and other treatment approaches emerge (including engaging through shared explanations, teaching self help, rehabilitation and personal adaptations, and restoring self-identity) and we’re likely to become less frustrated and hopeless. The recovery based system transformation gives us the opportunity (and in California some funding) to incorporate these approaches.

Rachel Remen writes movingly of her experiences as a doctor in the book “Kitchen Table Wisdom.” She followed in the footsteps of numerous other family members into medicine, but she turned out differently because she has struggled with severe Crohn’s disease since her teens, a recurrent inflammatory bowel illness that caused her recurrent diarrhea and required numerous surgeries to treat. She says she became a “wounded healer” and has gone on to work with people with chronic and terminal illnesses to help them find meaning and with burnt out doctors to help them find meaning.

She tells one story of a man she was working with who had cancer and was receiving chemotherapy. Every week he would come into the clinic and sit talking with his oncologist for twenty minutes while the chemotherapy flowed into his vein. After awhile it became clear that his cancer was not going to respond to the chemotherapy and his doctor told him he didn’t need to keep coming in any more. The patient asked if he could keep seeing the doctor anyway, but the doctor told him that there was no point. There was nothing more he could do for him. The patient felt such a loss he would’ve been willing to have continued to take highly toxic, ineffective chemotherapy just to spend time with his doctor. As chance would have it, the oncologist was also working with her because he felt he didn’t have anything to offer his incurable patients. He never realized the impact he was having on their lives.

An acute illness model tends to blind us to many ways of helping people, and it tends to hinder us from finding meaning.

The recovery movement has grown rapidly (and resisted efforts to change its name) because recovery is hopeful. Many people – patients, families, even staff – are desperately thirsty for hope. Unfortunately, most professionals don't feel the hopeful about recovery. We equate recovery with cure and most of our patients have incurable illnesses. We consider the entire recovery movement to be unrealistic, naïve, or even manipulative. Recovery with chronic illnesses is not dependent on cure. Patients can recover from a heart attack without their cardiac muscle regrowing. Patients can recover from a stroke without their neurons regrowing. And patients can recover from schizophrenia without their neurochemicals regaining balance. They recover when their lives are rebuilt not when their illnesses are cured. We can help them rebuild. There's hope after all.

There's a catch to all this: Illnesses don't recover, people do. We can directly cure illnesses, but we can't directly "recover" people. They have to be the center of their own recoveries. We can help give them hope, empower them, promote self responsibility, and create opportunities for meaningful roles, but they have to do the actual work of rebuilding. That's why the recovery model is "consumer centered" and "consumer driven." They have the starring roles. We're the supporting cast.

CONSUMER'S NAME:
RATER'S NAME:

MIS #:
DATE:

MILESTONES OF RECOVERY SCALE

Please circle the number that best describes the current (typical for the last two weeks) stage of recovery for the member listed above. If the member has not had any contact (face-to-face or phone) with any program staff in the last two weeks, please check here and indicate the consumer's LAST KNOWN stage of recovery and the date of the last contact that any staff have had with the consumer: _____/_____/_____

1. "Extreme risk" – These people are frequently and recurrently dangerous to themselves or others for prolonged periods. They are frequently taken to hospitals and/or jails or are institutionalized in the state hospital or an IMD. They are unable to function well enough to meet their basic needs even with assistance. It is extremely unlikely that they can be served safely in the community.
2. "High risk/not engaged"- These people often are disruptive and are often taken to hospitals and/or jails. They usually have high symptom distress. They are often homeless and may be actively abusing drugs or alcohol and experiencing negative consequences from it. They may have a serious co-occurring medical condition (e.g., HIV, diabetes) or other disability which they are not actively managing. They often engage in high-risk behaviors (e.g., unsafe sex, sharing needles, wandering the streets at night, exchanging sex for drugs or money, fighting, selling drugs, stealing, etc.). They may not believe they have a mental illness and tend to refuse psychiatric medications. They experience great difficulty making their way in the world and are not self-supportive in any way. They are not participating voluntarily in ongoing mental health treatment or are very uncooperative toward mental health providers.
3. "High risk/engaged" – These people differ from group 2 only in that they are participating voluntarily and cooperating in ongoing mental health treatment. They are still experiencing high distress and disruption and are low functioning and not self-supportive in any way.
4. "Poorly coping/not engaged" – These people are not disruptive. They are generally not a danger to self or others and it is unusual for them to be taken to hospitals and/or jails. They may have moderate to high symptom distress. They may use drugs or alcohol which may be causing moderate but intermittent disruption in their lives. They may not think they have a mental illness and are unlikely to be taking psychiatric medications. They may have deficits in several activities of daily living and need a great deal of support. They are not participating voluntarily in ongoing mental health treatment and/or are very uncooperative toward mental health providers.
5. "Poorly coping/engaged" – These people differ from group 4 only in that they are voluntarily participating and cooperating in ongoing mental health treatment. They may use drugs or alcohol which may be causing moderate but intermittent disruption in their lives. They are generally not a danger to self or others and it is unusual for them to be taken to hospitals and/or jails. They may have moderate to high symptom distress. They are not functioning well and require a great deal of support.
6. "Coping/rehabilitating" – These people are voluntarily participating in ongoing mental health treatment. They are abstinent or have minimal impairment from drugs or alcohol. They are rarely being taken to hospitals and almost never being taken to jail. They are managing their symptom distress. They are actively setting and pursuing some quality of life goals and have begun the process of establishing "non-disabled" roles, but they often need substantial support and guidance. They may be productive in some meaningful roles, but they are not necessarily working or going to school. They may be "testing the employment or education waters," but this group also includes people who have "retired." That is, currently they express little desire to take on (and may actively resist) the increased responsibilities of work or school, but they are more or less content and satisfied with their lives.
7. "Early Recovery" – These people are actively managing their mental health treatment to the extent that mental health staff rarely need to anticipate or respond to problems with them. Like group 6, they are rarely using hospitals and are not being taken to jails. Like group 6, they are abstinent or have minimal impairment from drugs or alcohol and they are managing their symptom distress. With minimal support from staff, they are setting, pursuing and achieving many quality of life goals (e.g., work and education) and have established roles in the greater (non-disabled) community. They are actively managing any physical health disabilities or disorders they may have (e.g., HIV, diabetes). They are functioning in many life areas and are very self-supporting or productive in meaningful roles. They usually have a well-defined social support network including friends and/or family.
8. "Advanced Recovery" – These people differ from group 7 in that they are completely self-supporting. If they are receiving any public benefits, they are generally restricted to Medicaid or some other form of health benefits or health insurance because their employer does not provide health insurance. While they may still identify themselves as having a mental illness, they are no longer psychiatrically disabled. They are basically indistinguishable from their non-disabled neighbors.