Person Centered vs. Illness Centered 1 Exploring Recovery: The Collected Village Writings of Mark Ragins

Since the passage of Proposition 63, the Mental Health Services Act in 2004, I've traveled all over the state "getting people up to speed" on recovery. I usually begin my presentation by talking about why I think recovery is real and not just the fashion of the month before I go on to the four stages of recovery. Along the way I started showing an overheard that visually shows the difference between an illness centered perspective and a person centered perspective, "the planets diagram" that appears at the end of this paper. It seemed to be a good bridge between the inspiring stories in the four stages and the need to make concrete recovery based program changes they were facing. I kept expanding that portion of the presentation because it was such a useful foundation for everything else they needed to change. Here's the text of that bridge.

Person Centered vs. Illness Centered

(2006)

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.



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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



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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 form 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.



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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. SAMSHA'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.

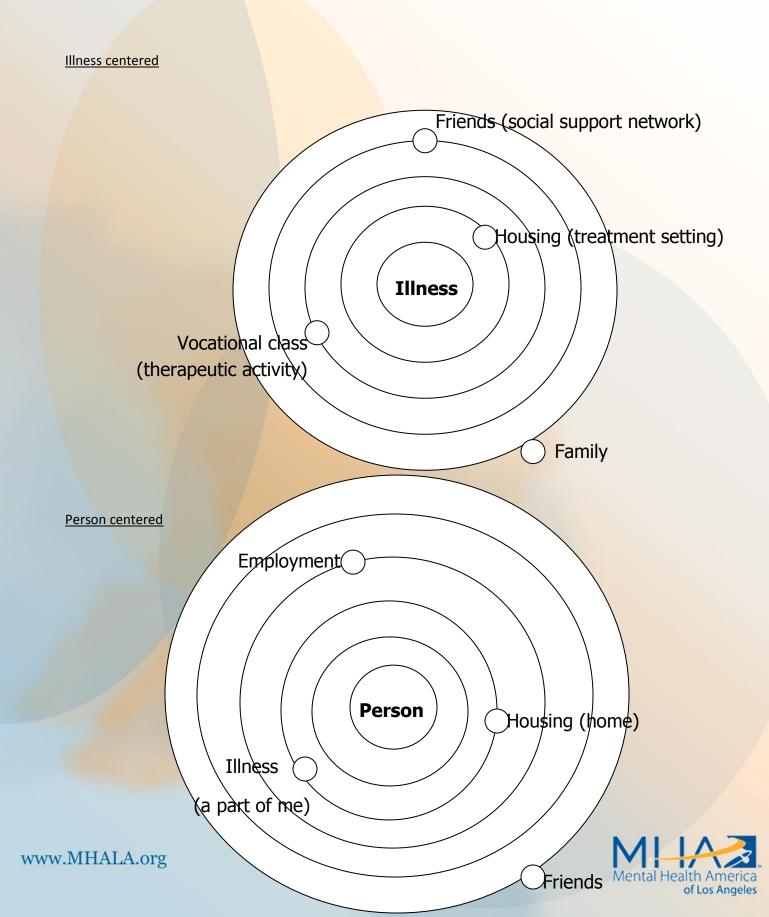
All recovery based services are transitional, though usually not time limited. The person moves on as they grow and change, not as their illness responds to treatment. They graduate and leave the system, when they are able to manage their lives, including their illness if it's still there, not when they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



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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.



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



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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	The relationship only exists to treat the illness
throughout and continue even after services	and must be carefully restricted throughout
end	keeping it professional



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