

*I still think that if I ever become famous it will be because of the Kubler Ross' stages approach to recovery I created in that booklet. It has a power that SAMHSA's "10 Fundamental Components of Recovery," for example, never will though this approach incorporates many of them and, in the end, makes it clear why we value what we do and why it works. Also, as we move on to system transformation, the hospice movement is a concrete, inspiring example of how observations of people led to a theoretical organization which led to a new treatment culture which led to a new system of care.*

*And I suppose I can admit that it also works because people like the stories.*

*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 overhead 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.*

## **The Four Stages of Recovery (2002)**

Recovery has four stages: (1) hope, (2) empowerment, (3) self-responsibility and (4) a meaningful role in life.

### **Hope**

During times of despair, everyone needs a sense of hope, a sense that things can and will get better. Without hope, there is nothing to look forward to and no real possibility for positive action. Hope is a great motivator, but for hope to be truly motivating, it has to be more than just an ideal. It has to take form as an actual, reasonable vision of what things could look like if they were to improve. It's not so much that people with mental illness will attain precisely the vision they create, but that they need to have a clear image of the possibilities before they can make difficult changes and take positive steps.

### **Empowerment**

To move forward, people need to have a sense of their own capability and their own power. Their hope needs to be focused on things they can do for themselves rather than on new cures or fixes that

someone else will discover or give them. To be empowered, they need access to information and the opportunity to make their own choices. They may need encouragement to start focusing on their strengths instead of their losses. Sometimes they need another person to believe in them before they're confident enough to believe in themselves.

"Readiness" often occurs only in retrospect after they have done something successfully, so waiting until a person with mental illness is ready to move on can often be stagnating and disempowering. Often people have to experience success before they believe they can be successful.

### **Self-Responsibility**

As people with mental illness move toward recovery, they realize they have to take responsibility for their own lives. This means they have to take risks, try new things and learn from their mistakes and failures. It also means they need to let go of the feelings of blame, anger and disappointment associated with their illness. This is a particularly difficult stage for people with mental illness and their caregivers. Old patterns of dependency must be broken, and mental health professionals need to encourage clients to take charge instead of settling for the ease and safety of being taken care of.

### **A Meaningful Role in Life**

Ultimately, in order to recover, people with mental illness must achieve some meaningful role in their lives that is separate from their illness. Being a victim is not a recovered role, and frankly, neither is being a survivor. Newly acquired traits like increased hopefulness, confidence and self-responsibility need to be applied to "normal" roles such as employee, son, mother and neighbor. It is important for people to join the larger community and interact with people who are unrelated to their mental illness. Meaningful roles end isolation and help people with mental illness recover and "get a life."

This series of stages can provide a roadmap, albeit a fluid one, of the process of recovery that can be applied, specifically, to helping people recover from having a serious mental illness. For me, it has been a much better roadmap than the medical model's version. Although the medical model relies on objective, measurable signs and symptoms and scientifically defined illnesses, psychiatric histories rarely feel "real." On the other hand, subjective, experiential stories of recovery almost always do. I have heard many moving accounts by people with serious mental illness who have described to me what it is like to travel on a road to recovery.

This booklet is about the ways mental health workers can help people with mental illness build their roads to travel on.

### Stage 1: Hope

Last year, Marty, a 40-year-old Village member with schizophrenia, was dragged in to see me by his father who was also his conservator. Marty had spent much of his life locked up. He put on his “best face” to see the doctor, even though things were going poorly for him at home. He began with, “Everything is fine. The medication is working very well. You can just give me refills and save your time. I’ll be fine.” I talked with him leisurely, trying to get to know him better as I would a new friend. I introduced him to other staff and members and offered to share my popcorn.

As he watched and listened to me, he grew more and more confused and anxious. He didn’t understand why I neither moved to hospitalize him nor wrote him a prescription. Finally, he blurted out, “What do you want from me? Just tell me what you want and I’ll do it.” I thought for a moment and then said, “I want you to hope. I want you to hope that there can be more to life than staying out of the hospital. I want you to hope that you can use medication to relieve some of your suffering. I want you to hope that your self hasn’t been swallowed up by your illness and you can recover the things that make you special.”

My words were something he couldn’t fight against. There was no threat or power struggle. The next time he came back he said, “I’ve thought about what you said, and I want to go back to college.” Since then, he’s started using his medication more regularly, going out socially, working on his fears and moved into his own apartment. It has been a slow process, with many ups and downs, but his recovery has begun. It began with hope.

#### Questioning traditional views

Some of my colleagues may say I’m being a charlatan, giving unrealistic hope to people with schizophrenia. But, here’s my justification. Over many years, there have been numerous studies, with varying results, on the “natural course” of schizophrenia. In America during the 1840s, there was a widespread belief that God would heal people and apparently three-fourths of the people with schizophrenia in moral treatment hospitals recovered and went back to their lives in less than one year. In Germany during the 1890s, Kraepelin observed that the lives of people in his neurology hospital took a uniform deteriorating downhill course with no hope of recovery.

**Exploring Recovery: The Collected Village Writings of Mark Ragins**

Recent longitudinal studies in Maine and Vermont by Courtenay Harding, Ph.D., showed that at least half of the people released from back wards of state hospitals during the 1960s recovered and became functional again once they were back in their communities. In our present era, most people with schizophrenia are stabilized on medication and receive Social Security disability benefits. Less than 3 percent ever get off benefits and become self-supporting. It appears that the course of schizophrenia can be dramatically altered by how we respond to the illness.

Unfortunately our didactic training and our professional experience tend to reinforce negative, hopeless stereotypes. Professionals are taught Kraepelin's observations that schizophrenia is a chronic deteriorating illness even though there has been a century of studies in a variety of countries and settings that contradict Kraepelin. The longitudinal outcome studies, like Harding's, are simply not taught or widely accepted by professionals. Courtenay thinks professionals don't believe the data because it contradicts their daily experiences. Professionals often don't have contact with their clients after they have recovered.

I met a woman in Florida who took me out scuba diving. Afterwards, as we were washing off the equipment, I confided in her that I was a psychiatrist. She confided in me that after breaking up with a boyfriend she'd become paranoid and heard voices for about a year. She had been diagnosed with schizophrenia, hospitalized several times and treated with Mellaril, an antipsychotic medication, for several years. She had ultimately recovered completely and hadn't had any problems in the last 10 years. She certainly didn't fit my, or any other professional's, image of a person with schizophrenia. She never returned to see any mental health professionals after she recovered. As a result, no professionals ever saw her recovery.

*Re-examining "successful" treatment*

Both professional training and public education campaigns designed to reduce the stigma associated with mental illnesses carefully teach that schizophrenia is a genetically based, chemical brain disease that isn't anyone's fault. Unfortunately, this message gets translated to mean that every one is helpless when it comes to treating or overcoming mental illness.

When I was a psychiatric resident at the University of Southern California, I worked with a young Japanese-American man with paranoid schizophrenia. He wouldn't accept that he had this disabling, permanent condition. He wouldn't take pills except when he felt nervous or couldn't sleep. He wouldn't apply for Social Security disability payments and kept trying to use his accounting and computer skills to go back to work. Invariably, he would get paranoid, accuse his co-workers of spying,

destroy his work, and lose his job. He was an ongoing burden to his family with whom he lived, and they felt helpless and overwhelmed.

I worked very hard to establish a trusting relationship with him over the year I worked with him. I helped him to understand his illness as a biological condition and accept its limitations with less shame and blaming. It wasn't his fault; it wasn't anyone's fault. He began taking medications regularly and stabilized his symptoms. He applied for and received disability benefits and stopped trying to work. His family was very grateful.

Unfortunately, it seemed like most of the life had been taken out of him; he became passive and slowed. The days all passed uneventfully for him. I was left with a heavy feeling in my heart and wondered to myself if I'd actually helped him with my "successful" treatment. I had no exposure to rehabilitation or recovery and, at the time, I couldn't even visualize any other treatment outcome. My supervisor reassured me I'd done a good job. He told me that if I wanted to help my patient deal with his demoralizing inactivity I could couch it as early retirement or remind him he needed to avoid stress because of his illness.

#### *Believing in the possible*

The Social Security Administration once returned an SSI application I had filled out because I had written the word "hopeful" under prognosis. They said if the applicant's doctor had a hopeful prognosis then maybe he wasn't really permanently disabled. In an ironic way, they were right. One of the best ways to ensure permanent disability is to have a hopeless doctor. I've met many "disabled" people who wouldn't try anything new, including work, because their doctor said they couldn't do it. I've seen many people accomplish things that I thought, with all my professional experience and training, were impossible. I have entirely stopped telling people they won't be able to do something.

During my early days at the Village, Dan, a member who had lived in a board and care home for 15 years, said he wanted to move into his own apartment. As a well-trained psychiatrist, I knew his move was impossible. He'd had paranoid schizophrenia for 20 years and regularly complained about the people in the alley watching him and getting ready to attack him. At the time, I knew he was too ill to live independently.

Dan's caseworker was Clara, a feisty 60-year-old Puerto Rican woman who had run a bar when she was 19 and worn out three husbands. We hired Clara without any college degree because she'd done a good job raising a developmentally disabled daughter and was an outspoken church organizer. She also livened up our dances.

Without the benefit of higher education, Clara didn't know that Dan's moving into his own apartment was impossible. She began helping him find an apartment. Dan's sister called to complain, saying that her brother had paranoid schizophrenia and, if he moved into his own apartment, he would relapse and get re-hospitalized. It had been tried 15 years ago. Dan's sister felt that he needed to stay in a board and care so that someone would take care of him. Clara said she understood her concerns but that she worked for Dan and not for her. If Dan wanted to get an apartment, she was going to help him get one. I certainly wasn't going to tell Clara not to help him after that.

Clara did everything she could to help Dan succeed in an apartment. They walked the streets together looking at rentals. She helped him fill out applications, move, manage his money, do laundry and go shopping. She even helped him plan a housewarming party. All of this help was given as training so Dan gradually took over doing more and more by himself.

Unfortunately, several months after Dan moved, he called in a panic saying that poison gas was being pumped into his apartment and he had to get out of there. With the benefit of my education and training, I knew this was the relapse and likely hospitalization I'd been expecting. Without the benefit of my education and training, Clara went to his apartment to find out what was going on. She found a leak in his gas pipes. Poison gas was indeed being pumped into his apartment. She put Dan in a hotel for two days and hassled the landlord to fix the pipes. Eight years later, Dan was still living in his own apartment and doing everything for himself – even though I knew it was absolutely impossible. (Thanks for the memories, Clara.)

At the Village, I see things happening all around me that previously I would have thought impossible. I see recovery happening. It seems that people with serious mental illness can recover in ways I never dreamed of, especially if they can build their sidewalks with a combination of new, better medications and a good recovery-based program. I think it is rational to be hopeful. In fact, it seems much more rational to me to see the potential for recovery in each new person rather than assigning them a life of disability payments, unemployment, dependency, social isolation and segregation.

Mental health professionals uniformly regard people with severe mental illnesses as hopeless. This is because we spend virtually all of our time working with people when they are at their worst. Tim, a nurse we recruited from a psychiatric hospital, came to the Village for a job interview. One man Tim had known as a raving psychotic in the hospital waved hello at him. He was amazed to see people whom he had seen as severely ill in the hospital leading normal lives outside of it. Tim said he simply didn't know that was possible. That was the moment he got hope and decided to work with us. Hopeful staff create hopeful members.

*Seeing a positive image of the future*

One of our Village members, Ellen, has obsessive-compulsive disorder and psychosis. (By the way, neither Ellen nor I could fit her into a clear diagnosis even after Ellen compulsively read and reread the DSM IV.) Ellen taught me that there is a difference between hope and a positive image of the future. On one hand, she has hope that she can recover so she keeps coming to me and searching out new approaches and medications. On the other hand, she has no image of what she would be like if she recovered. Consequently, Ellen doesn't actually follow any of my advice or make any of the changes, usually involving facing her anxieties, because she doesn't see how it could possibly help her.

Most of us need an image of our goal before we are ready to undertake anything difficult to reach it. I know I would never have stayed in medical school if I hadn't had an image of myself as a doctor. My present life is nothing like I imagined it would be, but once I started on the path to medicine, choices kept appearing. Most of the time, goal imaging must precede goal planning.

Our team took Pam, another Village member, out to a celebratory lunch. Pam, who has an undiagnosable psychiatric disorder, had returned to college and we were celebrating the "A" she got on her first test. At the lunch, Pam said she wanted to thank me. I asked Pam what I had done. It seemed to me that she'd done all the hard work. She said that every time she came to see me and started complaining about her boyfriend, her agitation, her medication or me, I talked about how I could see her as a student at Long Beach City College. I'd remind her that registration was coming up or offer to call a friend of mine in the disabled students office for her. After a while, it seemed like a real possibility. She started to see herself as a student, too. Pam said that once she could see it, she could go out and do it.

Charlie is another example of how visualizing a different future can be motivating. At 24 years old, he had been receiving Social Security benefits since his first manic-depressive psychosis at age 19. He told me about his latest episode of depression and how he had been stuck in bed, and as a result, had missed yet another job interview. I responded by saying that I knew he was frightened about losing his disability benefits or about getting psychotic again, but that actually his symptoms were greatly improved.

I said that he could stay on SSI benefits indefinitely, but asked if that was really how he visualized his future. What would it be like to be 44 and still on disability? What else could his life become? Later that week, Charlie called his case manager and told her about his conversation with me. Charlie said he

had thought a lot about what I'd said and decided he didn't want to be disabled forever. He could do more.

Charlie asked his case manager to set up another job interview. He went to the interview, followed up aggressively and got the job. When he told his mother about getting the job, Charlie was surprised that she wasn't as frightened about his getting off SSI or getting sick again as he thought she would be. She was very supportive. For a long time, I had been urging Charlie to see if taking less medication made him less sleepy. After getting the job, Charlie agreed to try a lower dose.

Nothing makes me feel quite as good about being a psychiatrist as actually reawakening hope in someone.

#### Getting emotionally inside

When I was a resident, I developed a growing sense of confidence by handling a large set of difficult "cases." I collected an amazing array of "war stories" and could out-duel most of my fellow residents with enthusiastic tales of the unusual, the bizarre and the complex. What I failed to experience were the people who made up these "cases." I hadn't given any thought to what it must be like to have these conditions. What I failed to experience was compassion and empathy.

Before we, as mental health professionals, can help people form visions for their future, we need to know them as people and not just as diagnoses. Our objective assessment of the signs and symptoms of their illness will not help them imagine recovery in their future. As John Strauss at Yale urges, we need to do a subjective assessment, which is similar to the assessment an actor does when he tries to get into a role and understand the character's inspirations and motivations. In order to do this type of assessment, the professional needs to get emotionally inside the skin of someone with a serious mental illness, and that type of empathetic connection frightens many of us.

Bill, a man in his early 30s who has schizophrenia, came into my office late one afternoon. He held up his hand with his palm facing me and asked, "What do you see?" I was tired and answered unenthusiastically, "Your hand." This didn't satisfy Bill. He said, "No, no. Be more specific. What do you see?" I said, "Okay, I see the swirls of your fingerprints, the creases where your fingers bend, and those lines that are your love line and life line." Pointing from his eyes to the back of his hand, he said, "When you can see nails and knuckles and hair, then you'll be able to help me because you'll be seeing the world from my side instead of yours."

As a mental health professional, I feel it is our obligation to understand our members' worlds so that we can figure out how to be helpful to them. It isn't their obligation to understand our world with its DSM IV and its rules in order to receive help from us.

When I ask Village members what the staff did that was the most helpful, they never say, "It was that clever combination of Resperidone, Depakote and Serzone you prescribed." They always recall some moment of human kindness or a time when we believed in them. They recall the moment when our walls were down or when we were genuinely happy for them or even when we cried. We helped them when we were real. That's when they could tell we had hope.

### **Stage 2: Empowerment**

Empowerment is a popular term in mental health with most programs claiming to "empower" their clients. But mental health programs seem to have many differing definitions of empowerment and practices designed to promote it. Judi Chamberlin, advocate and author with the National Empowerment Center, identifies the key elements of empowerment as including access to information, ability to make choices, assertiveness and self-esteem. Using this definition, I feel that we, as professionals, do some things that help promote empowerment for the people we serve and other things that have the opposite effect and need to be changed.

As a psychiatrist, I found that changing my focus from treating illnesses to helping people has been the most important step I've made toward promoting empowerment. At first glance, this change may seem semantic or "politically correct," but in practice there is a big difference. Here are two extreme examples that illustrate this difference.

Shock therapy can be a very effective treatment for the illness of psychotic depression. With only modest side effects, it can dramatically improve a mute, starving, catatonic, suicidal person within a couple of weeks. Shock therapy is, on the other hand, usually a very bad experience for the person who receives it. Patients often feel traumatized, stigmatized, out of control and frightened by the memory loss associated with shock therapy. Some suffer ongoing nightmares and blame the shock therapy for everything bad that happens to them afterwards. They are often more frightened of needing more shock therapy than of the depression returning.

On the other hand, when a street outreach worker connects with a homeless person who has schizophrenia by talking to him regularly or bringing him a lunch and a blanket, it can be a very good experience for the person. This type of street outreach can help people begin the long, slow road back to belonging to society. It can help them build enough trust to accept other types of assistance like medication, housing, substance abuse treatment and employment services. However, giving someone a sandwich twice a week is a very bad biological treatment for a neurochemical illness like schizophrenia.

### Seeing the person not the case

Helping people doesn't mean ignoring their illnesses. It means treating their illnesses as part of their entire life. "Seeing the person not the case" is essential to empowerment.

When I have an appointment with another doctor and I tell her I'm a doctor, I am treated as a colleague, not a patient. Even if the doctor has never met me before, she often won't charge me. Her staff makes sure I'm comfortable while I'm waiting and helps me fill out the forms. The doctor often asks me about my practice and is friendly. We work on my history and diagnosis together. The doctor will go over lab tests and x-rays with me – even though I couldn't read an x-ray to save my life. She will often tell me the advantages and disadvantages as well as her opinion of each treatment option, and then give me a choice of what treatment I want.

If I went to the same doctor and didn't tell her that I am a doctor, I would be treated much differently. Now I'm a patient. I have to fill out forms on my own. I am left alone to wait for my few minutes with the doctor. Now I'm an unreliable historian and my sense of humor is a distraction rather than an enjoyable quality.

The doctor recites a memorized description of my condition, prescribes a treatment without including me in the process and then urges me to comply with her orders. In both examples my illness is treated. In the first, I am a person; in the second, a patient. In one, I am empowered; in the other, I'm not. To be empowering as a psychiatrist I needed to stop turning people into patients.

### Re-evaluating the role of the doctor

Several years ago, I was on a panel at a conference presenting on medications. I had never met the man and woman I was with on the podium. Both of them had chronic schizophrenia and their role on the

panel was to talk about their experiences with medication. My first impression was that both seemed rather slow and dull with very little to say. They were satisfied seeing their psychiatrists for fifteen minutes once a month.

The presentation was dying, so I asked them about the rest of their lives, aside from medications. As it turned out, the woman was in a bowling league, baked cookies for her Sunday school class and knew a great deal about the bus system in Hollywood. The man used to volunteer in the basement of the Hall of Records where the archival photographs of Los Angeles are kept. They both literally came to life as they talked about their interests.

Once they got started, they talked and talked, animated and engaging. Finally I interrupted them to ask why they said that they had nothing to say to their psychiatrists when they had so much to say to me. They replied that their psychiatrists never asked about their interests. Their psychiatrists just asked about their voices, their paranoia and their sleeping habits. The psychiatrists asked about their illnesses, not about their lives.

In medical school, I was taught the clinical model for approaching my work. A patient comes to see the doctor with a problem or weakness. The doctor and patient would have an unspoken agreement that the doctor was allowed to poke and prod the patient and that the patient would tell the doctor things he wouldn't dream of telling his best friends. In general, if the patient submitted to the doctor's will, then the doctor would use his strength and expertise to cure him.

My role as an aspiring doctor was to make a medical diagnosis, which I might or might not share with my patients depending on whether or not I thought they could handle it. I would prescribe some sort of treatment, usually medication. The patients would consent to comply with my treatment plan and sign a waiver that said they wouldn't sue me if anything went wrong. During return office visits, I would assess the symptoms of the patients' illness, any serious side effects they might be experiencing and whether they were complying with my treatment orders. This process would continue until I had cured, or at least stabilized, the patients' illness.

#### *Practicing medication collaboration*

At the Village, I developed an entirely different recovery model of medication collaboration. Now, a person comes to me with a goal, something they want to accomplish or change about their lives.

Through the process of planning this change together, the member and I discover things that I can do to be helpful. It may be that some of the knowledge I have about neurochemical illnesses, emotional conditions, interpersonal relationships or social service systems may be helpful. Or, my knowledge about playing the piano, using the Internet or the Los Angeles Lakers may help. Hopefully, I'm aware of some treatments, usually including medication, that may assist members in reaching their goals. I consent to help them reach their goals by educating them and offering them choices.

The Village members I collaborate with may choose to include something I've offered them in their plan if they think that my assistance will help them meet their goals. When they return (and virtually all do; I can usually find something helpful to do, even if it's just writing a letter, filling out a bus pass form or giving them a hug!), we discuss how their plan is coming along, not how their illness (that they may or may not think they have) is being treated. There is very little reason for "noncompliance," because they, not I, are making up the goals and the plans.

If they choose not to take medications, I continue to see them and try to help them with their goals, instead of becoming coercive or getting into a power struggle with them. I may need to build a stronger relationship, do more education, create more goals or connect medications to their goals more clearly.

#### *Giving meaningful information and choices*

My relationship with George is a good example of this style of collaboration. George came to me asking for help because he was hearing voices. I didn't initially ask him what was causing the voices. Instead, I asked him how his life would be better if he didn't hear the voices. He told me that he wanted to date women, but whenever he tried to talk to a woman the voices taunted him, calling him stupid, fat and ugly. He said it was so demoralizing he didn't even want to try anymore.

To help George, I used my knowledge of psychosis and anti-psychotic medications. I also used my limited knowledge of women. I told him women might be more likely to go out with him if he was cleaner and dressed nicer. A car would help, too. We could work on those things while we were working on the voices. I wrote down a list of 10 possible medications. I told him the most common side effects from the medications on the top of the list were stiffness and shaking and from the medications on the bottom of the list were sleepiness, dizziness, dry mouth and blurred vision. I asked, "What do you want to try?" I also told him we could start with a larger dosage that might work faster, but have more side effects, or we could start with a smaller dosage that might work slower but be easier for his body to adjust to. He chose 5 mg. of Haldol at bedtime.

From the beginning of our relationship I was giving George meaningful information and meaningful choices. I was treating him like a colleague and partner. I was empowering him. When he returned, I didn't begin by asking how the voices were. I asked if he'd talked to any women, since that was his goal. He said "no." Although the voices were much quieter, his hands were shaking so terribly that he was too embarrassed to talk to anyone. I realized that even though I had successfully treated his illness, I hadn't helped him reach his goal. George and I reviewed the medication choices again and kept working together to improve his life.

My relationship with Gail is another example of medication collaboration. She has had severe schizophrenia since her early teens. She was once catatonic for an entire year and it seemed unlikely she would ever leave the state hospital. Nevertheless, she did get out and, with the help of hugs and acceptance from a dear staff person named Joannie, she began building a life. However, she still had to cope daily with disturbing voices and paranoia despite high dosage anti-psychotics.

When Clozaril was released Gail wanted to try it. I was reluctant because of her seizure disorder and Clozaril's numerous and even potentially lethal side effects. We learned about the risks and benefits together, reading papers, watching videos and even conference-calling an expert. The expert and I advised against the Clozaril, but the decision was ultimately hers. How could we judge whether voices or seizures were worse for her? When she tells this story, she emphasizes the moment when she got to tell the doctor what she wanted for herself. She was empowered in that moment and she chose Clozaril. Surprisingly, at very low dosages her psychosis went away for the first time in 20 years without any bad effects. She's used her power to go on to marriage, owning a condo, working full time and getting off SSI.

#### Learning from obstetrics and oncology

Two other medical fields, obstetrics and oncology, have already achieved substantial empowerment of their patients without the aid of any dramatic technical or clinical breakthroughs. The practitioners in these fields have instead transformed their priorities, their roles and their relationships. I believe the conceptual shift underlying this transformation was when obstetricians began viewing pregnancy and giving birth and oncologists started seeing surviving with or dying from cancer, not only as medical conditions, but as profound life altering experiences. How the patient experienced these events became as important as how they were clinically treated. Serious mental illnesses are clearly also profound life altering experiences affecting almost all areas of life. How people experience these events are as important as how they are clinically treated.

This conceptual shift has given rise to five very practical, empowering changes in both obstetrics and oncology:

1. Increased treatment collaboration. Education about their conditions and the treatment options and active choice (rather than compliance) by the patients has been emphasized. Women are given classes about the process of pregnancy and delivering and about the various interventions (including anesthesia) that are available. They actually choose what they want. Similarly, cancer patients are taught about cancer, surgery, radiation and chemotherapy, and they make choices. The goal is increased understanding of their conditions and collaboration on a “birthing plan” or a cancer treatment course. The professionals welcome, indeed foster, their patients’ efforts to learn about and participate actively in their treatment. The professionals become consultants or coaches assisting patients to manage their conditions instead of managing it for them.

2. Increased use of self-coping techniques. Patients have been encouraged to actively treat themselves as an adjunct to medical treatments. Lamaze breathing techniques to reduce pain and muscle strengthening exercises to avoid tearing are now commonplace for pregnant women. Visualization techniques for treating cancer are growing in popularity.

3. Increased use of natural supports. Including family members or friends as part of the childbirth experience or hospice team is now routine. Isolating patients with only professionals around them during their most difficult times is very rarely a medical requirement.

4. Increased use of home or home-like settings. Home births and birthing centers where patients bring their own belongings are replacing sterile delivery rooms. Home health and hospice settings are replacing hospital wards for cancer patients. The medical equipment, while still often essential, is embedded in a home-like environment instead of becoming its own environment.

5. Increased use of peer support. Many pregnant women (and their partners) go to classes with other pregnant women, sharing their experiences and supporting each other. Cancer survivor groups and grief groups for families of people who die from cancer are common. Especially for cancer patients, a sense of pride at being a “cancer survivor” has replaced a sense of shame. These groups can be activity directed or informational. To be supportive a group does not have to be exclusively a “support group.”

As I analyzed these factors I began to realize that empowerment is not just an abstract value. It is an actual set of practices. If these five practices are employed, empowerment will result. These five practices are also a pretty good description of psychosocial rehabilitation and have already been developed for mental health.

The mental health establishment, however, has decided that these practices are to be used only after the professionals do the “real” clinical work of treating patients’ symptoms and “stabilizing” them rather than using the practices as the foundation of treatment. Undoubtedly there were obstetricians and oncologists, surgeons and nurses, radiation therapists and social workers who needed to be dragged into these empowerment practices. If they did it, so can mental health professionals.

### Putting empowerment into practice

At the Village, we take empowerment very seriously and try, through self-evaluation, to improve continually and add to the empowering qualities of our program. Here is a partial list of some of our empowering elements:

- Members set their own goals and choose what parts of the program (including medication) to participate in.
- Every six months, members are given the opportunity to switch teams, case managers and psychiatrists without providing a justification for the switch.
- Staff shares bathrooms and lunch tables with members. We don’t have staff lounges or any part of our building that is off-limits to members.
- Members play an active role on our advisory board and our grievance committee.
- Staff meetings, trainings and retreats are open to members.
- We hire a significant number of full-time regular staff who have a mental illness and/or are recovering from substance abuse.
- Members often participate with staff in doing presentations about the Village.

**Exploring Recovery: The Collected Village Writings of Mark Ragins**

- We survey members individually and anonymously as part of staff evaluations.
- Members can drive the Village vans after passing a driving test and gaining insurance approval. In fact, the vans are mostly driven by members who are paid for driving other members to events.
- Members can read their own charts whenever they want. They can even write in them.
- We have a social activity calendar based on what members want to do (and will help with) and not based on what we think is good for them.
- We provide scholarships to members to attend professional/educational conferences.
- We have a Village band (named “The Delusions”) that is made up of both members and staff.
- We are affiliated with a consumer run network of self-help clubs, Project Return: The Next Step.

This is not meant to be a complete list of empowering practices. There are probably other programs that do even more or different things to empower their members. Ideally, a program would conduct ongoing evaluations and continually attempt to increase its empowering elements.

All of these practices do require that staff give up some sacred power and the division between themselves and members. Many of our staff were anxious and expressed concern about nearly all of these practices. And, of course, there have been a few problems that needed to be worked out in their implementation. However, nothing very bad has happened as a result of these practices and a great deal of member empowerment has taken place.

*Offering respect and honesty*

During my years at the Village, I have come to realize that true empowerment requires helping people get “real world” experiences. Teaching people skills, including emotional skills, in a treatment setting rarely builds confidence. There’s a big difference between sitting in a group talking about how artistically talented someone is and helping that person actually set up a successful exhibition of his artwork. I believe success builds empowerment more than positive thinking does.

Setting up artificial successes or over-celebrating meaningless accomplishments is more likely to be perceived as condescending than empowering. To empower people, give them a chance to come to bat and a good pitch to swing at and don't ever drop their fly ball on purpose. To empower people, believe in them through numerous "failures" and don't give up on them even if they want to give up on themselves. Encourage them to try something new and support them in their efforts. Often, they will be pleasantly surprised to discover skills and "power" they didn't know they had.

Only an empowered staff can empower the people they work with. If a program's staff culture is dominated by fear of risks and blame avoidance or if it fosters lack of initiative by demanding that staff follows orders and policies without questioning them, they won't feel empowered. Staff needs to have power in order to give it away and needs to model being empowered to be believable. "Institutional helplessness" isn't a growth medium for empowerment. What if I had told Clara not to take any risks helping Dan get his own apartment?

Late one evening the medical director of a local psychiatric hospital approached me in the doctors' parking lot. He said that he'd been watching the Village staff, trying to figure out why the Village succeeded with so many patients that no one else seemed able to help. He said he thinks that the special way all of our staff, from top to bottom, show respect to our "patients" and treat them like important people may be the reason. I think he is right. At the end of the day, offering respect and honesty to people with mental illness may be the key to empowering them.

### Stage 3: Self-Responsibility

Once people have sufficient hope, see a vision for the future and feel empowered, they can take control of their own lives again. They can assume more responsibility for themselves.

Bonnie, a woman with manic depression, told me that she used to become very psychotic and violent. The police would tie her up and take her to the hospital. The hospital wasn't so bad. All the people there were very nice to her and they took care of everything. They made sure her belongings were safe. They fed her, bathed her, clothed her and gave her medication. And it worked. Within a week or two, Bonnie felt much better, thanked them and went home, back to her life as it was before. Within a

couple of months, she would become psychotic and violent again and get dragged back to the hospital. After a while the hospital staff started blaming her for being a “revolving-door patient.”

It took Bonnie three years to figure out what was wrong with this process – she had never been included in any aspect of her own recovery. She didn't know why she was suffering, how it connected to the rest of her life and what changes she'd have to make to stop the cycle. The clinicians in Bonnie's life were spending all their energy and resources forcing her to get short-term symptom relief instead of engaging her in a process of self-understanding, self-responsibility and change.

As professionals, we are taught to take care of others. We see our jobs as helpers, protectors and comforters. Unfortunately, being someone's caretaker is often at odds with helping him or her learn self-responsibility.

#### Supporting risks instead of avoiding stress

Another way that we, as mental health professionals, may keep our clients from assuming self-responsibility is by convincing them to avoid stressful situations. Among mental health professionals, one of the most pervasive rationales for supporting stabilization instead of recovery is that stress causes relapses and re-hospitalizations. This is actually very hard to demonstrate.

It is easier to demonstrate that avoiding relapses is connected to taking medication, having an ongoing supportive case manager or therapist, having a good social support system (friends, staff and/or family) and not abusing drugs. Actually, negative symptoms (low energy, poor motivation, emotional blunting, distancing and passivity) are better predictors of disability than positive symptoms or relapses. Negative symptoms are clearly worsened by lack of stimulation, low expectations, inactivity and hopelessness (or in other words, by the absence of stress.) A member recently told me that he'd made a mistake in quitting his job. Sitting at home doing nothing was causing him far more paranoia than the stress of work ever had.

Personally, I think that avoiding stress reduces recovery more than it reduces relapses. By avoiding stress, members are avoiding the opportunity to build a social network and a life that will, in turn, help them battle their symptoms. Often, protecting people from stress is protecting them from the opportunity to grow. Clinicians are often too frightened to “permit,” let alone encourage or support,

people with mental illness to follow the “normal” developmental path of risks and growth. “Normal” people all fail repeatedly and keep growing anyway.

Sometimes I wonder if we, as mental health professionals, aren’t protecting ourselves from the pain of our clients’ failures more than really protecting them. At the Village, our members may not succeed until their fifth (or 10<sup>th</sup> or 20<sup>th</sup>) attempt to get a job, live in their own apartment, stop abusing substances or take their medications responsibly. I believe it is our job to keep hope alive and support our members through ongoing stress and risk-taking, failures and successes as they recover.

### Engaging not forcing

Shifting priorities from care taking to promoting self-responsibility has enormous implications for the use of forced treatment. One day, Hawk’s mother called the Village’s homeless outreach team begging for help. Hawk was seriously psychotic and refusing to take medications. His family had been forced to keep him out of the house, but felt they had to keep protecting him and maintained contact by letting him live in his car parked in front of their house. The psychiatric emergency team had talked to Hawk, decided he didn’t meet involuntary treatment criteria and told Hawk’s parents there was nothing they could do.

Tim, a Village nurse, went out and sat in the car with Hawk. He kept doing this for several weeks until he built a relationship with Hawk. Finally, Hawk agreed if Tim brought some pills to his car he’d take them. Several weeks later he agreed to come into our program for a shower and a lunch. After a while he started working at the Village making lunches for other homeless people. His mother sent us a beautiful thank you letter saying we were the help she’d prayed for. It is almost always better to begin engagement by entering someone’s world rather than by forcing treatment. Admittedly, when someone is in serious danger, I have been forced to try both at the same time.

Stories like Bonnie’s and Hawk’s have helped to convince me that our overriding goal as mental health professionals must be to promote self-responsibility and recovery rather than to take care of people, relieve their distress and protect them. We must look out for those times when we’re destroying hope, taking away power, or decreasing self-responsibility in the name of helping and taking care of someone. I have a natural desire to fix things for others. Sometimes it takes all my emotional effort to let someone struggle with working things out in their own way (especially when it isn’t my way) so they can grow.

Supporting member choices

At the Village, we don't spend a lot of time and resources assessing whether members are ready to do something or not. In general, our philosophy is that they are ready "enough." If members want to do something, we support them. There is nothing more devastating than being told you're not ready. In truth, no one is ever really ready to do anything important. (I dare anyone who has married, had children or rented their first apartment to disagree.) Instead of assessing members' readiness, we assess the support they will need to be able to do what they want to do.

When I talk with members, I routinely ask them where they would like to live. Even if they have few independent living skills, they rarely say, "I'd like to live in a crowded, run-down place with other people with mental illness where the staff will take care of me and can hospitalize me if I act out. Or, I'd like to share a room and live without privacy or the opportunity for comfortable sex." They usually say they'd like to live in their own apartment or with a sexual partner (just as "normal" people would say).

In the Village's supportive housing program, staff helps members get an apartment and adds whatever support is needed to make it work. Examples of supportive services are becoming the members' payees and helping them pay the rent and utilities, securing in-home services to clean and cook, arranging for meals-on-wheels or helping the members do their shopping, and staying connected with frequent home visits and phone calls.

If the members "fail," then they help us assess what needed supports were missing, what they need to change in order to succeed next time and what was wrong about the match with that particular apartment. And, then we try it again. Some members continue to need heavy support; others need very little. Either way, they are living where they want to be and they are living as independently as possible.

Trying, ready or not

I am convinced that helping members live where they want to, whether they are "ready" or not, is highly preferable to expecting them to progress through the standard "continuum of services" offered by most traditional programs. In a "continuum of services" model, clients are required to earn their independence by succeeding in a series of residential settings ranging from the most structured to the least structured. Movement in the spectrum requires constantly changing rooms, roommates and

support staff. In the meantime, people aren't living where they want to live, and they're being taken care of rather than being taught how to take care of themselves. Power struggles, unhappiness and "non-compliance" are the inevitable by-products.

At the Village, supportive services are designed to be training services, not care-taking services. While the members are getting the services they need, the staff is actually teaching members how to do things for themselves. For example, if someone asks us to call the Social Security office for them, we will offer instead to sit with them while they make the call, or we will look up the number together so they can call, or we will role-play making the call before they make it. We don't just do it for them, if at all possible.

Teaching takes more time, but ultimately it promotes self-responsibility.

### **Looking at our own internal stigma**

One of the greatest barriers to helping members experience self-responsibility, and hope and empowerment for that matter, stems from staff who aren't in touch with their own feelings about mental illness and haven't examined their own internal stigma.

A few years ago, I gave a lecture to a group of third year psychiatry residents. I described how one of our staff members, Paul, had previously run a cookie store staffed entirely by people with serious mental illness. One of the residents sheepishly asked if it was safe to eat their cookies. She assured me that she had never met a cookie-poisoning mentally ill person, but it was clear that she had maintained an emotional distance from her patients during her first two years of training, and her irrational prejudices and stigmas had survived intact.

I think one of the most powerful anti-stigma experiences is working alongside people with severe mental illnesses. It forces professionals to relate to them differently from the way they do in a clinical context. They begin to see things about them other than their illnesses and begin to value their strengths and talents instead of their weaknesses and symptoms. At the Village, we hire a number of people with serious mental illnesses, not as consumer counselors emphasizing their illness, but for a variety of jobs, depending on their skills and interests, just the way we hire people without serious mental illnesses. Departments of mental health should be the largest employers of people with serious mental illness and they almost never are. How can we encourage members to believe they are capable of assuming responsibility for themselves if we don't believe it first?

One day at a conference, Judy Cooperberg, one of my favorite people and the director of the Mental Health Association's Antelope Valley programs, showed me a book of poetry she'd written. As I read it I realized she had been repeatedly severely psychotic, almost killed herself several times and had considerable psychiatric inpatient experiences. Prior to that moment, I had no idea that she had ever had a mental illness. She had been a friend and co-worker. More of us need startling, anti-stigma experiences like that moment was for me.

I have now met a psychiatrist with schizophrenia, a psychologist with schizophrenia, even an ophthalmologist with schizoaffective disorder that the medical establishment is vigorously stopping from returning to work despite her recovery. I know a journalist in New York who collects and publishes life stories of doctors and lawyers and other professionals with serious mental illnesses of all kinds, but no one believes him. They think he's making it all up. Of course, they don't believe he has schizophrenia either.

### **Taking risks isn't easy**

Many people with mental illness, their families and even many of us, as staff, have been traumatized over the years by failures and have quit taking risks. Our reluctance to take risks, especially if it is coupled by a lack of hope, will shut down our members' movement toward recovery.

My sons are now teenagers. Soon I will try to teach them to drive. I realize this is a risky process, but I'll do it anyway because driving is an essential ingredient to succeeding in adult life. I like this analogy of teaching driving to assisting in mental health recovery because you can't teach someone to drive by just telling them how, or having them sit next to you while you drive, or even by using a sophisticated classroom simulator. You have to let them drive while you sit next to them sharing the experience. You don't even get your own steering wheel. Professional driving instructors get a passenger side brake, analogous to our involuntary hospitalization powers, for stopping the action in emergencies. But even then, you can't press the brake too much or your student will never learn to drive.

To continue with the analogy, if my son crashes the car and causes substantial damage, my style as a driving instructor will change. I'm likely to become angry, less tolerant and more over protective, and my effectiveness as a teacher will probably decrease. (I may even display "high expressed emotion.") If my son crashes the car and I'm paralyzed from the waist down, I may no longer be able to teach him to drive at all. Quite simply, I would have been too traumatized and too hurt to keep going. I wouldn't be willing to put myself through that kind of trauma ever again.

Once, after I shared my driving analogy with an audience in Louisiana, a woman raised her hand. She said she was a social worker and the mother of a man with manic depression who had crashed his car and been badly injured. Although it had been very difficult for her, she knew that in order for him to recover, he'd have to risk driving again. She figured if she could support risk taking for her son, she could do it for her clients, too. The audience was clearly moved by her story in a way I never could have moved them.

Sometimes it is very hard to keep hope alive and keep everyone involved taking risks long enough so that recovery can eventually happen. Two years ago, Jill was brought, rather uncooperatively, to join the Village by her parents. Jill and her parents had suffered through 20 years of Jill not taking medications regularly, drinking excessively and being abusive to her parents. Jill felt that her parents "owed" her because she was ill, and her parents felt they had made things worse over the years by giving too much and becoming too enmeshed. The staff worked closely with Jill's parents to help them distance themselves and they enjoyed their first vacation in years. Meanwhile, Jill suffered from depression, drunkenness, severe weight loss and paranoia. During her first months at the Village, she even got beaten up out on the streets.

After about a year, Jill agreed to take medication and for the first time in a decade was willing to go into a substance abuse rehabilitation program. After the first month, as Jill struggled with sobriety, she started having problems with the staff at the alcohol recovery program. Everyone's hope began to wane. When Jill started drinking again, her parents had had enough. They withdrew her from the Village and locked her up in a hospital, hoping for a new doctor to cure her. The new doctor recommended shock therapy. They needed a new hope.

#### *Taking risks requires relationships*

For many clinicians, a natural fear of risk is compounded by a fear of getting sued and losing their license. I believe that lawsuits are more the product of someone feeling betrayed and powerless than the product of bad things happening – every program will have some tragedies. If all the people involved (members, families and staff) actively share in the struggle, have an appreciation for the preciousness of the member and agree that taking risks is necessary for recovery, I feel there is much less likelihood of lawsuits.

A number of years ago, a Village member named Carol suddenly developed Neuroleptic Malignant Syndrome (NMS) – an unpredictable, rare (and sometimes fatal) side effect of the anti-psychotic medication she needs in order to function. Carol, her family and the Village staff all struggled through several months of hell. She almost jumped out a window in the hospital. She was on a respirator and

**Exploring Recovery: The Collected Village Writings of Mark Ragins**

got pneumonia. Every day brought new danger and fears, but we were all sharing our observations and feelings together. I gave Carol's parents an article in a medical journal about her condition, and we talked about our observations and hopes. As Carol improved, we involved her in every part of her recovery. After her full recovery, Carol and her parents didn't want to "sue the doctor who almost killed her" – a common reaction to NMS. Instead, they were thankful that I'd helped save her life and return her to full functioning. The true payoff of our partnership came two years later. Carol was in the hospital for pneumonia. Her mother came to visit on a Sunday afternoon and noticed the early warning signs of NMS that I'd taught her and that the doctors and hospital staff all missed. She called our emergency system and warned me. I got emergency hospital privileges, saw Carol within hours, agreed with the diagnosis and transferred her to the ICU. This time her recovery was much shorter and easier.

When one of the Village members has died, staff and members have all shared in the grief and participated in the memorial service. Often, we have received profound thanks, prayers and even donations from the deceased member's family. Relationships are, in my opinion, the strongest protection against lawsuits, and since our program places its highest priority on relationships, I believe we are at less risk than if we acted self-protectively.

Almost paradoxically, even though the Village philosophy encourages a high risk/high support approach to programming, I have experienced substantially fewer tragedies here, especially suicides, than I experienced when I worked in programs that promoted stabilization and self-protection. Helping build a strong life is ultimately far safer than trying to protect a weak one.

As professionals, we need to take responsibility for the consequences if we do something negligent, abusive or destructive. Likewise, if members do something negligent, abusive or destructive, they need to take responsibility for the consequences, too. If they're making progress toward self-responsibility, they'll also be moving away from blaming others and suing when things go wrong.

### Considering others

One of the final steps in assuming self-responsibility is becoming considerate of others. Once people with mental illness stop blaming others for their unhappiness, they can begin to experience empathy for their parents and others who have also been affected by their illness.

**Exploring Recovery: The Collected Village Writings of Mark Ragins**

Manny was brought in by his father to see me because Manny had stopped taking his medication again and was becoming obviously manic. His father told us that, although he understood it was Manny's life and Manny's decision whether or not to take medicines, he had decided that Manny couldn't continue to live with him if he chose to stop his medication. He wanted the Village to help Manny find a new place to live because he wasn't willing to live with him through another one of his manic episodes.

I shared my driving analogy with them, trying to help Manny understand his father's reaction. To my surprise Manny's father broke down into tears. He said to Manny, "That's just how it is for me. I keep seeing you sitting in the middle of that freeway talking to God and I can't handle it." Even more surprisingly, Manny got up, hugged and comforted his father.

Over the next few days, Manny decided to restart his medication and stay with his father. Over the years, he's used his medication more and more effectively and has not been seriously manic. He's lived in several places and worked most of the time. Interestingly, by telling his son how he felt, Manny's father was able to help his son learn how much he was hurting someone he loved and take much broader responsibility for his decisions. Manny and his father still have a close, loving, mutually respectful relationship.

In many ways, achieving self-responsibility is the roughest part of any road to recovery. It requires people with mental illness to change dramatically how they view themselves, their loved ones, their caregivers, their illness and their future. It requires them to take charge of their lives and to leave the blame, anger and disappointment behind as they head toward taking responsibility for themselves.

**Stage 4: A Meaningful Role in Life**

One of the Village's core values is that there must be a place for everyone in this world. Our director, Martha Long, has instilled this value in us. "No one belongs neglected in the streets or locked up because there is no place for them in our community. Don't give up on anyone. Keep trying, even if you've tried everything." Martha even helps us think of the next plan to try.

One day I received a piece of paper in my mailbox that said "Niche License." The member who put the paper in my box is a very lonely woman, especially since her mother died. She usually lives in an elaborate world of her own creation. She said she put "niche licenses" in everyone's mailbox because

everyone deserved to have a niche in life. She explained that this was my license to find my own niche and claim it as mine.

One of the tragedies of serious mental illness is that it often deprives people of their roles in life, their niches. They often drop out of school or have problems working. Their peer and family relationships are disrupted and their life turns sharply from where they thought it was going. The mental health system generally offers people with mental illness only one role – the role of chronic mental patient. Accepting the existence of a mental illness usually seems helpful to me; however, accepting the role of chronic mental patient usually seems harmful to me.

### **Searching for new roles**

I bought an aquarium at a yard sale to set up by my desk at the Village. I decided to take Yvette along with me to the pet store to help me pick out some fish. Yvette is an extremely psychotic young woman who spent all of her time sitting at her board and care home imagining other worlds. I knew she liked fish and that she hadn't left the board and care in about a year. After a great deal of encouragement, she and her roommate got in my car, and we went to the fish store where I let them pick out the fish for my tank. Then, we went to the Village to put the fish in the aquarium by my desk. When we had finished, she thanked me, saying that when she was in the store, she forgot, for a little while, that she had a mental illness and that I was a psychiatrist. She said she felt like a normal person, if only briefly, for the first time in years.

As people with severe mental illnesses begin to recover, they often search out new roles for themselves. At the Village, we use a lot of group pressure to encourage them to find positive roles. Often the easiest new roles available to our members – drug dealer, prostitute, battered wife and homeless wanderer – are the ones we spend the most time trying to discourage. Fortunately, we do have four powerful, positive areas to promote: work, love and sex, families and children, and spirituality.

### **Work**

Work plays an important role in every phase of recovery. Certainly very few things are as empowering as a paycheck, especially a first one. When one of our members showed me her first paycheck, there was an incredible glow in her eyes and pride in her voice. She was amazed at what she'd been able to do and it began to change her ideas of who she was. That's true empowerment. A "real job" also develops self-responsibility. It teaches and strengthens skills. And it helps us define meaning in our lives. In our society, we generally identify ourselves to new social contacts by what we do for a job. As problematic as "psychiatrist" is as a role, "chronic mental patient" is vastly worse. Without a job, it is difficult to get

out of that role. At the Village, we tell members the best way to get away from the world of mental illness and boredom is to get a job.

### Increasing expectations

When the Village began, our concept of employment was creating small, three hours per week stipend jobs for members. These jobs were designed so members wouldn't earn more than \$65 per month and wouldn't disrupt their SSI payments. Most of the members didn't put in much effort at these jobs and did them quite poorly. When Paul Barry came to the Village to take over the employment program, he changed all the jobs so that members worked every day and at least 15 to 20 hours per week. I protested that these people were too impaired to work so many hours. If they couldn't perform for three hours per week, how could they possibly manage daily jobs for 20 hours per week?

Since the psychiatrist doesn't run the employment program, we did it Paul's way. Sure enough, within several weeks, the vast majority of Village members had either quit or been fired. But before I could say, "I told you so," the strangest thing happened. Most of the members reapplied for their jobs, and I was busy figuring out with them what additional supports or changes they needed to succeed this time. Again, most of them failed and lost their jobs, but most reapplied for a second time. Ultimately, after as many as five or six tries, the same people who couldn't work for three hours a week could work these 20 hour a week jobs and do them well.

People with severe mental illness, like the rest of us, need an income in order to survive and avoid homelessness. Most get their income from Social Security. Everyone on SSI who considers minimum-wage work is faced with a difficult financial decision. If someone gets off SSI entirely and then relapses in the future, it can take six months to restart their benefits, during which time they might become homeless or hospitalized again.

Needless to say, most stay on SSI and yet, most people with severe mental illness can also work, at least periodically. The Social Security system needs a major overhaul if more people are going to shift their role from patient to worker.

Work is incredibly useful at every stage of recovery and essential for the meaningful role stage. Yet, few mental health programs invest many of their resources in employment services. Frequently,

Departments of Mental Health don't consider employment their responsibility. Medicaid funding usually won't pay for employment services as part of a treatment plan.

If employment services occupied a central, integrated role in all mental health programs, recovery would be a more common client outcome. At the Village, we support work heavily. We spend 25 percent of our budget on employment services, as contrasted with other programs that spend, on average, less than 5 percent. We have some of the best employment outcomes anywhere. However, because of SSI, we are forced to rely almost entirely on "recovery" benefits to motivate our members to work instead of economic benefits.

### *Love and Sex*

The search for love and sex is a powerful human urge and one of the most difficult for anyone to prepare for, attain and maintain. However, in the search for meaningful life roles, many of the most important roles are tied to romantic relationship – "married," "single," "not dating anyone" and "not dating anyone seriously," to name a few.

When people with severe mental illnesses are isolated from a "normal" social life, they usually retain their urges for love and sex, but have limited access to experiencing them. "Therapeutic" environments and communities pervasively exclude love and sex. I think there are many reasons underlying this practice, ranging from revulsion at the idea of "crazy" people having "perverted" sex to a desire to prevent mentally ill people from reproducing or having children they can't care for.

As professionals, we tend to see mentally ill people more as children than adults and we have a desire to protect them from exploitation and the "stress" of a relationship. Consequently, it is almost impossible to find a mental health program that goes beyond sex education and prevention of venereal diseases to truly support the search for love and sex.

At the Village, sometimes we focus on our members' romantic struggles from a "therapeutic" point of view, such as dealing with the effects of childhood sexual abuse or rape (both of which are common in our members). More often, however, we come from a "community" point of view. We maintain a strict rule against staff having sex with members, but inside that boundary, we try to create a normal, sex and love promoting community.

We have dances and go out to clubs. We try to “fix people up.” We’re confidants. We goad members into dating. We try to help couples “work it out.” We’ve even had a wedding reception at the Village. Obviously, we discourage prostitution, sex in the bathrooms and all sexual behaviors that are illegal or unsafe. Putting it all together, we try to create a community that supports the love and sex that our members are often deprived of in our larger community.

## Family

After several years, we began to realize that when members started to recover, they often reconnected with long lost family. They reconnected because they loved and missed their families, not because they wanted to redress old wrongs or engage in therapy with them.

From a “treatment” point of view, families are important only within the context of how they impact their family member’s mental illness. Are they supportive or sabotaging? Do they have high or low expressed emotion? Are they educated about the illness? Are they enabling or intrusive or isolating?

From a “recovery” point of view, families are important because they are the members’ families and people in a family love each other. At the Village, when we work with members and their families, we do not treat “dysfunctional family dynamics.” We work with members to help them assume their normal family roles as sons, daughters, sisters, brothers, mothers and fathers.

Theories about mental illness ranging from schizophrenogenic mothers and high expressed emotion families to patient as family burden have all missed the point. They all address illnesses, not people. A woman with chronic depression was sitting next to me at a National Alliance for the Mentally Ill sponsored lecture about family burden. Halfway through the lecture, she said to me, “This is making me feel very sad and small. I knew I’d been difficult for my family at times, but now I’ve literally become a ‘burden’ to be labeled and quantified.” I think it is important for the mental health system to be an effective locus of treatment and care giving so that families can go back to being families.

### Going home again

In our society, adolescents normally rebel and distance themselves from their families. They find a peer group that helps them form their values and roles. The results are obviously different if the peer group is a street gang than if it is college roommates. After awhile, if things go well, people return to their

families, proudly showing off their adulthood. Unfortunately, many people with serious mental illnesses lose their peer groups in adolescence, when they need them most. The Village staff and members try to provide a replacement peer group, with positive values, not a replacement family. Experiencing this replacement peer group and the resulting feelings of independence often makes members want to reunite with their families.

Some of these reunions have provided my most touching moments at the Village. A Village member, Ted has schizophrenia and has been seriously addicted to street drugs. Over the last 20 years, he has been homeless, on and off, and has been hospitalized repeatedly. As Ted began to improve, he wanted to reconnect with his sisters, his ex-wife and his 18-year-old daughter – none of whom he'd seen in 15 years. With lots of support, encouragement and even advice from the Village staff, he was able to reconnect and make several trips back east to see his family.

After a while, everyone in his family began to realize that Ted wasn't a psychotic, drug-crazed monster. When he was in a car accident with his sister, Ted was the one who maintained his cool. Later on when his other sister became very ill and frightened, she called Ted to come comfort her with prayers. Ted was finally able to recreate a whole set of meaningful roles for himself aside from his illness; he was able to claim his niche in his family.

### *Children*

Many of our members have had children of their own and, unfortunately, many of them have been separated from their children. The profound pain and sense of loss caused by being separated from their children is often the most powerful emotion in their lives. Trying to help our members keep their children and build their own families is one of our most complex and difficult challenges.

No longer can we give primacy to our members' needs and wants – we must include the children as well. The erratic Department of Children's Services and the dependency court exert enormous power in these situations, often in highly stigmatizing, arbitrary and destructive ways, in my opinion. What is usually needed for members to succeed as parents is to build an extended family – a single, poor, unsupported mentally ill parent is an unlikely formula for success. Unfortunately, these government entities seldom focus their efforts and resources on strengthening families.

### *Extending families and support*

At present, against all odds, one of our members with schizophrenia and substance abuse is raising her infant daughter with indispensable help from her mother and grandmother. The Village staff and other members are part of her extended family as well. I brought a childcare book, a toy and her regular antipsychotic injection to her baby shower. We approach increasing parenting skills not with parenting classes, but by having staff, members, family or friends working side by side with the member to help raise the child by modeling effective parenting. We expect some bumbling, but we also expect love and commitment. That's how "normal" people become parents, too.

Issues of past childhood abuse often resurface when members raise their own children and need to be worked with. These issues can destroy efforts to build an extended family. A member's mother who was heroin addicted and abusive hardly makes for an appealing grandmother. Almost paradoxically, if that grandmother has changed and is now very good with her new granddaughter, it can be very painful for the new mother to see her daughter getting the loving she lacked as a child. The individual variations we've seen are endless.

There are sometimes additional medication issues. For example, we had an extended family meeting one day to help one of our members decide whether to stay on the potentially dangerous, but for her, lifesaving medication Clozaril while pregnant. Despite the risks, she took the Clozaril throughout and she is now raising a beautiful 6-year-old daughter. Last month I bought a candy bar from her daughter for her softball team.

I count among my greatest accomplishments the families we've saved. Our Village needs babies to admire and children to run laughing through our hallways. It's hard for us to be truly alive without children around us. And, yes, as an African proverb and recent book state, sometimes it does take a Village to raise a child.

### **Spirituality**

Several years ago, Village staff and members decorated individual squares of cloth that were then sewn together into a giant Village quilt. To the staff's surprise, many of the members' squares included references to God, Christ or other spiritual content. Until it was staring us in the face, we hadn't really seen how important spirituality was in their lives. Many of our members have turned to spirituality in an effort to find meaning in their illness and their suffering. Many have spiritual descriptions of the symptoms of their illnesses. One man I know describes himself as having "spiritual schizophrenia" because he has struggled to find peace within the church he loves.

As professionals, we have been very hesitant to help our members deal with their spiritual side. By doing this, we separate ourselves from a potentially meaningful and healing part of their lives. We're so afraid of doing harm or breaking rules that we choose ignoring or neglecting this part of them as our default path.

### Pursuing a path

At the Village, members choose the spiritual path they want to pursue and staff try to provide them with the support they need. With the exception of memorial services and other rituals that hold our community together, the Village rarely provides spiritual programs because we want members to connect with one of the many spiritual programs available in the community. Sometimes we need to work to help these programs become more welcoming to our members.

We do have to be careful (especially if we personally have a cherished path) that we're really building a sidewalk where they want to walk and not pushing them toward one we've pre-ordained for them. Occasionally staff members' personal beliefs make it hard for them to support the spiritual path a member might want to pursue. When this happens, the staff explains the conflict openly and asks another staff to work with the member around this issue. There's enough diversity among the Village staff to support almost any path a member may choose.

### Creating a spiritual atmosphere

As staff, we do not give members answers to specific spiritual questions, but instead try to create an atmosphere where positive spiritual values – like acceptance, love, hope and compassion – can thrive. When our community faces a tragedy, like a death, we are able to draw upon this spiritual atmosphere to create memorial services or other rituals that strengthen our sense of belonging and caring about each other. Within this atmosphere, members can discover their own spiritual strengths and healing. Many people attribute their recoveries to someone “really believing in me” or “seeing something inside me I couldn't” or “really caring about me, not just because it was their job.” These moments, whether conceptualized spiritually or not, clearly impart spiritual core values. Many staff rightly cherish these special “miraculous” or “inspiring” moments in their work. We need to focus on how to make them happen more often.

**“Get a Life”**

**Exploring Recovery: The Collected Village Writings of Mark Ragins**

There are, of course, a multitude of other meaningful roles and niches in life other than those bound by work, love, family and spirituality. Our director, Martha Long, is fond of telling visitors that our program can be summed up as a “get a life” program. Certainly that describes a more meaningful destination for our road to recovery than “get well soon.”

Many mental health workers complain that their clients are unmotivated. They struggle with helping their clients set goals and getting them to follow through on their plans. They often conclude that their clients are too ill and need more treatment before they can work on rehabilitation. The problem may actually be that their clients haven't progressed through the stages of recovery far enough to “get a life.” More action may be needed on hope, empowerment or self-responsibility. Once someone has progressed through the stages of recovery, “get a life” can be a very powerful motivator, and it can stimulate motivation for all kinds of growth, healing and change.

At a hospital where I have admitting privileges, the staff was doing a weekly treatment plan for a depressed woman (of course, they didn't include the patient in the planning). Her psychiatrist said that the social worker should help her find a stable, sober place to live so she could go to day treatment regularly. I said that getting a stable, sober place to live should be the goal of her treatment plan, not the prerequisite for it. Our goals need to be “quality of life” goals not “mental hygiene” goals if our members are going to be motivated to pursue them. After all, life is the goal of treatment, not the other way around.

### Removing obstacles

As people encounter obstacles on the way to getting a life, they may actually become more motivated to get treatment to overcome those obstacles than they were before. Jorge, a middle-aged Latino man with schizophrenia, never wanted to take medication. He felt all of his “delusions” were religious beliefs and experiences. Even after I got his priest to bless his medication, Jorge stop taking it after a short while. He did, however, have a strong work ethic and asked to be hired in the Village's café as a dishwasher.

Even though he was very psychotic and, therefore, by standard reasoning, “not ready to work,” our café manager hired him anyway. A couple weeks later, Jorge came to me because he was having trouble concentrating at work and asked if the medication I was always trying to persuade him to take would help him concentrate better. I told him it probably would, and he's been taking medication regularly ever since.

Another man with schizoaffective disorder and severe drug abuse began getting his life together. He cut down dramatically on drug abuse and moved off the streets into an apartment. He then came to me and said, "I'm not getting into as much trouble anymore and I'd like to go back to school, so I don't want to sleep my days away any more. Do you have any medication that would work on the voices and paranoia, but not make me sleepy like my Mellaril does?" I certainly did.

Similarly, people may be more motivated to work on their emotional issues when those issues are getting in the way of something they want to accomplish. Mary Jane, a young woman with schizoaffective disorder, was feeling much better after I changed her medications and she stopped hearing voices. She was working as our receptionist and active in both Village and community social activities. She moved out of the board and care and into her own apartment. However, over the next several years, Mary Jane lost several apartments because she had abusive, disruptive boyfriends who moved in with her and caused her to be evicted. After losing her fourth apartment, Mary Jane became motivated to go to a therapist to work on her low self-esteem and her dependency issues with men.

At the Village, we have a variety of approaches to emotional issues. We think there are many ways that emotional healing can occur outside of the traditional once a week visit with a therapist. All of our staff tries to create "corrective emotional experiences" within their daily work and adult-to-adult relationships. I told one visitor to our program that we didn't do any group therapy. He replied, "Nonsense, this entire program is a giant group therapy. You're aware of everyone's psychodynamics and actively working on them. You just don't have any set room, time or attendance." We occasionally connect our members to therapists outside our program for more private healing. We also try to help members connect with other people, besides professionals, who might be emotionally healing for them. At our best, we're teaching people to be aware of their emotional issues and to actively choose, for themselves, good people to be emotionally connected to.

### *Losing a life*

"Get a life" can also be a powerful motivator for substance abuse recovery. We do not try to help members "bottom out" so they will stop using drugs. Instead, we help them build lives, "raising the bottom," so they'll have reasons to stop using drugs. Substance abuse is by far the single most important factor in "losing a life." More people are homeless, jailed, physically ill, psychiatrically hospitalized, hungry, evicted, fired from their jobs, kicked out by their families, have their children taken away and even die because of substance abuse than for any other reason.

The entire Village community is actively involved in substance abuse recovery. About a third of our members have ongoing serious problems with substance abuse. We incorporate into our daily lives a four-stage system (engagement, persuasion, active treatment and relapse prevention) that includes both “harm reduction” and “motivational interviewing” techniques. When a member abusing substances becomes motivated to stop, we usually enroll them in specialized residential substance abuse recovery programs in the community at large. At any given time, about 10 percent of our members are living in recovery programs. About one third of our serious abusers are now in serious recovery. This group has achieved some of the most amazing successes we’ve seen. They’ve got lives.

When Maurice was a homeless addict, he was surprised that we stuck with him, trying to help him get off the streets. When he was in early recovery, he was even more surprised that we offered him a job as an outreach worker. He had a reason to stay clean. The reasons have grown over the years. He is married, has a new Toyota Avalon, has an extensive striking wardrobe and has worked alongside me as a team personal service coordinator for several years. In 2001, he received a national award as the consumer case manager of the year.

### **Belonging as a meaningful role**

Years ago, I visited Lamp Community – a good drop-in program for homeless people with serious mental illness – in Los Angeles’ Skid Row and ran into a former “clinic patient” of mine. He had always done poorly at the clinic where I used to work. He had been quite psychotic, attended appointments erratically and taken his medications sporadically. I was happy and surprised to see him busily making soup. He seemed more coherent than I’d ever seen him. I greeted him and asked him where he was getting treatment now that he’d dropped out of the clinic. He answered that he was making soup. I said that I understood that but where was he getting treatment. He answered that he was making soup. Yes, but he must be taking medication to be doing so well. He answered that he was making soup.

I backed off for a moment and then asked him to tell me about making soup. He answered that all the people there were homeless and had no money. For many of them, the soup would be their only food of the day. He had to pull himself together to make the soup because they needed him. They were depending on him. In my opinion he had found his meaningful role in that community. He belonged there and that accomplished what traditional treatment never had.

Most mental health programs build their communities out of therapeutic and care taking elements (e.g. day treatment, groups, individual therapy sessions, and staff led social programs). People can belong to these communities only by taking on the role of the chronic mental patient. One of the main purposes of these communities is to provide a safe, protected haven, an “asylum,” away from the larger outside community.

### Shifting roles

When I was a medical student, I spent one winter at the Meninger Institute – a fancy, expensive psychoanalytic hospital in Topeka, Kansas. One snowy afternoon, I met Joseph, a 20-year-old man with severe catatonia. He would talk to others if they approached him, but if no one did he’d spend hours perfectly still in his slumped catatonic pose. Every day, the staff and patients went for a walk together. On this occasion, the psychiatrist, dressed in an expensive suit and wearing slick patent leather shoes, slipped and fell.

Joseph began to help him, guiding him around the slippery spots and holding him up. When we returned to the ward, the psychiatrist straightened up his clothes and returned to his role as psychiatrist and Joseph resumed his slumped catatonic pose and returned to his role as patient. If we want the people we are trying to help to become something other than chronic, dependent, helpless, mental health patients, we are going to have to become something other than chronic, caretaking, helpful mental health professionals. At times, this may mean shifting roles with them and finding ways in which we can belong together.

### Building a community

The Village builds its community out of the same elements that a normal community is built on: work and social relations, budgets, celebrations, rituals and shared experiences. People can belong in the Village community by working there, socializing there, dating there, serving on committees, leading social activities, giving presentations and, of course, by making soup. Our community is built for people, not patients.

We are a safe community where, like “Cheers,” everybody knows your name. Most of our members also have roles and “belong” in the larger outside community. Some members only return occasionally

for holidays, special occasions or in times of crisis. We are a community, or even a “family,” of adults, not children.

Several years ago, Wayne Munchel of our staff organized the Village’s first Golden Ducky Awards celebration. Following the example of the Academy Awards, we had a limousine and a red carpet. Richard Van Horn, CEO of the Mental Health Association, dressed up in a tuxedo and was the master of ceremonies. The staff and members took turns presenting awards for living independently, working, maintaining sobriety and graduating from school. There was even a local cable TV station filming. The pharmaceutical representative that helped pay for the ceremony broke into tears saying that successes like these are what selling medications really is all about.

I got to co-present the award for Team 2 Member of the Year to Tina. In a year and a half, she had left the state hospital to go to a board and care home and then into her own apartment. Tina had gotten off conservatorship and become her own payee. First she worked at the Village and then at McDonald’s. In her acceptance speech, Tina said she’d come to the Village with two goals. One was to find a place she could call home, to stop being homeless and to put down roots. The other was to work. She had accomplished both goals and she was so happy. She had progressed through all four stages of recovery, and we were honored to have helped her.

### **Spreading a Recovery Vision**

Recovery offers a new energizing vision for people with mental illness, their families and the professionals who serve them. The momentum is already building but, so far, the philosophy and values of recovery are only practiced in isolated pockets across the country. The mental health system, as a whole, is far from being recovery-based. Government funding mechanisms are still mired in a medical-necessity model that rewards symptoms and illness and discourages health and recovery. Most people’s training and values are still very much caretaking and medical-model. It can be discouraging at times.

Building a true recovery system is as revolutionary a vision as is building a criminal justice system based on forgiveness instead of punishment, or creating an education system based on love for learning instead of obedience to authority. We may have to implement our vision in small increments. Progress may be slow. Even if we can’t change the entire mental health system, there are things we can do in our existing mental health practices and programs that will promote recovery.

The Village is trying to be a comprehensive, integrated mental health service built on the recovery stages and values discussed in this booklet. Now after more than a decade, the Village has been successful in helping many people with serious mental illnesses recover and “get a life.” The Village’s members include those who have been homeless, in jail, in state hospitals and under conservatorship. The Village has become a recovery community. We have also been involved in numerous efforts to spread our principles and practice, hoping to work toward widespread system change.

Drawing from lessons we’ve learned at the Village, I recommend the following action steps:

- Create integrated services instead of fragmented, specialized services.
- Promote quality of life services – like money management and job coaching – instead of illness services.
- Evaluate services by measuring quality of life outcomes.
- Involve clients in every aspect of their treatment and recovery.
- Promote engagement instead of coercion.
- Promote never giving up on anyone by implementing “no failure,” “no discharge” and “no lost to follow up” policies.
- Encourage staff to take risks.
- Empower staff by giving them control over money to help people more directly and individually.
- Promote out-of-office activities.
- Hire numerous people with mental illnesses to work in a variety of jobs.
- Promote activities that have staff interact with people with mental illnesses in non-patient roles such as talent shows, sports teams, block parties and outings.
- Create and support consumer-run services.

During trainings, I’ve asked staff and clients at other programs to use the four stages of recovery as an auditing tool to assess which of their practices promote recovery and which hinder it. This type of assessment usually generates other action steps for programs moving toward recovery.

### *Becoming recovery workers*

Many of us bring experiences that can help us become good recovery workers. Some of us, like Dan Fisher, M.D. or Patricia Deegan, Ph.D. have had experiences with mental illnesses. Others have struggled with other illness. Virtually all of us have had some experience with tragedy and personal recovery we can draw on. Some of us have had experience with the 12-step recovery program and the mentoring role of sponsors. Others have considerable experience with psychiatric rehabilitation, like Bill

**Exploring Recovery: The Collected Village Writings of Mark Ragins**

Anthony, Ph.D. and Robert Liberman, Ph.D. or with psychosocial rehabilitation, like Village staff and me. Each of these experiences can enrich our approaches to recovery.

After years in the mental health field, many of us have forgotten why we got into this work in the first place. We've lost touch with our hearts. I do a training where I ask people to re-write their job description using recovery terms. They describe their jobs as being listeners, welcomers, spiritual grounders, hope instillers and risk encouragers. One responded poetically, "I help people remember what made their heart sing – and then help them do it again." One long-time caseworker said, "It's been such a long time since I've thought of myself in these ways. I'd almost forgotten." Most participants find their roles in a recovery system would be a return to why they got into this work, a return to their core gifts.

As mental health professionals, we often talk about feeling burned out. I agree with Patch Adams that burnout comes not from being too intimate with people, but from trying to keep them away from us. If we spend our energy erecting walls to keep the people we are trying to help at a distance and our hearts hidden, the passion in us dies.

But, if we reach out with compassion when someone suffers from severe paranoia or allow ourselves to cry when someone we care about dies from a heroin overdose, we will feel pain but we won't burn out.

One of the psychiatric residents who came to work at the Village had a sister with manic-depressive illness. Even so, it was only at the Village, with our lowered boundaries and increased emotional intimacy, that he was really forced to look at how he felt about people with mental illness. When he no longer held them at arm's length, he discovered that, contrary to his fears, he very much enjoyed sharing their lives. He went on to work at a large homeless shelter in New York and a fellowship in public psychiatry.

### *Influencing attitudes*

At the center of spreading the recovery vision is influencing attitudes both inside and outside of the mental health system. As Bruce and Gina Anderson, who are specialists in community integration, explained to Village staff several years ago, there are two parts to our job. Sometimes our job is to help the people we work with be able to live better lives in our community, and sometimes our job is to help our community be a better place for the people we work with to live in. This means gradually changing

**Exploring Recovery: The Collected Village Writings of Mark Ragins**

a community that wants to exclude and forget people with serious mental illnesses into one that will welcome and value them. This is very difficult work, and it may take decades to accomplish, but it needs to be done.

Many years after Helen Keller's pioneering work, it is now common to see signs (many mandated by law) that say: "This facility is handicapped accessible," welcoming people with various serious illnesses. Someday, I would like to see signs posted that say: "This facility is psychosis accessible."

If we walk into a grocery store and see a man in a wheelchair working stacking cans on a shelf, we think, "Isn't that nice. Look at that man overcoming his disability and making a life for himself." We might even go over to shake his hand and compliment him. If we walk into a grocery store and see a man with Down's Syndrome working stacking cans on a shelf, we think, "Isn't that nice. Look at that man overcoming his disability and making a life for himself." We might even go over to shake his hand and compliment him.

But, if we see a man with psychosis, who is wearing tinfoil on his head and talking to himself, stacking cans on a grocery shelf, most of us don't think, "Isn't that nice. Look at that man overcoming his disability and making a life for himself." We are more likely to think, "I wonder if he's dangerous. Maybe he should be in a hospital." We don't go over to shake his hand and compliment him. We actively avoid him.

When we do go over to shake his hand and compliment him on overcoming his disability and making a life for himself, then we will be living in a world where almost everyone with severe mental illness can recover. And wouldn't we be proud to live and work in such a world.