

Dan Wiesburd is the father of a very pleasant man whose career at Harvard was derailed by schizophrenia. As a result, Dan has applied his substantial skills as an advocate, film maker, organizer, educator, and overall agitator to improving mental health services. His efforts were crucial to creating the legislation that funded the Village and he has continued to assist the Village over the years. In his role as publisher of the quarterly Journal of the California Alliance on Mental Illness (our state chapter of the powerful national family organization for mental health advocacy, education, and mutual support), he created an entire issue devoted to the Village in 1993. A variety of staff, members, administrators, and outside leaders submitted articles describing our rapidly emerging program including me. We still keep old copies of the Journal around to give to interested visitors since it captures the growing pains and the excitement of those early transformative years.

Each of us wrote about what transformations we'd made to work together in a psychosocial rehabilitation culture. My article focused on prescribing medications, because even at a program where the psychiatrist is encouraged to become involved in all aspects of a person's life, medication prescription is still takes most of my time. The concept that emerged "medication collaboration" in contrast to the traditional "medication compliance" has become one of my keystone concepts.

Partners in Medication Collaboration

(1993)

In medical school, I was taught to be a strong, helping professional, ordering medication for weak, helpless, dependent, sick patients, and then assessing their "compliance" with my regimen. To work in a psychosocial setting like the Village, to work with members' health instead of illness, strengths instead of weaknesses, I had to discard my white coat, my coat and tie, and even my professional distance. I have become a full member of the community, bringing my family to Thanksgiving dinner, playing basketball at the YMCA, being a customer at the mini-mart, and sweeping the streets in a neighborhood cleanup effort. I'm now the "Village Doctor".

My role with medication has become that of a consultant. I listen to what members say helps them, educate them about their conditions and medications, and, as much as possible, prescribe the medications, they choose and then assess with them the results of our "collaboration". For the majority of our members, we find personal goals and work together for them to function as well as possible in spite of their handicaps. This is a rehabilitation/recovery model instead of an illness/treatment model.

Over the first six months of the process, I worked with our members reviewing old records and experiences, getting to know them in a variety of settings, and I talked to other people who knew them. As a result, I changed the diagnosis of one third of our members, and changed entire classes of medication for about one third. I lowered doses for about one third, kept one third about the same and

raised the dosages for one third. I even stopped meds entirely for about ten percent of our members. As a result, by my evaluation, three quarters had better symptom relief and two thirds had fewer side effects. Fully half of those members who had a significant social or vocational improvement had a significant medication improvement that preceded it. Medication collaboration became a big part of their overall rehabilitation.

There are three common obstacles to “medication collaboration”:

- 1) Some members are using medication to achieve pleasant altered states of consciousness instead of using it to function better. These members often use illegal drugs and alcohol as well. I try to add substance abuse treatments to my medication visits. I often use long acting injections and medical management, handing out pills weekly or sometimes daily to avoid medication abuse. Ultimately I hold the members responsible for the results of their actions.
- 2) Some members are so demoralized that they would prefer to sleep through life and have their feelings anesthetized. I try to separate unpleasant feelings from symptoms of an illness. Primarily these members benefit from psychosocial rehabilitation; having some positive experiences, some positive interactions and feeling a growing sense of control over their illnesses.
- 3) Some members are so out of touch with reality or in such a denial of their illnesses that they are actually legally incompetent to make decisions about their medication. Our present law provides for hearings (“Reise hearings”) to involuntarily medicate members in this condition while they are in the hospital. I would urge that we lobby to extend these powers to outpatients. Some people are able to live in our community, but they’re incompetent to make decisions about their medications. Presently they are left to make very poor “non-decisions” and suffer the consequences. In the meantime, I try to enter their reality to try to helpfully incorporate medications into their lives in a way that makes sense to them from their point of view. I also sometimes videotape members to help them see reality.

Many times there are other partners in the “medication collaboration” process besides the psychiatrist and the patient: family, friends, landlords, board and care workers, etc. Once again, most of the time, if they are invited into the process, if their input is listened to, if they are educated and asked to help, they will also find common ground to work towards and enrich the process immeasurably. The change in style needed from me to call them, invite them to medication meetings, and make home visits has benefited the members substantially.

Once again, there are three common obstacles to medication collaboration:

- 1) Some people are so motivated by fear that they cannot focus on growth potential. Usually these fears can be easily justified. They’ve lived through past experiences either of violence and harming others or of suicide attempts and many other self destructive tragedies. The fear itself must be controlled first. This may require police assistance, moving particularly contentious relationships, like money management or medication management to our

- agency, or even physical separation. Our agency must prove itself adequate to respond to crisis to help the member maintain self-control. Emergency medications, the 24-hour beeper, and especially home visits have proven to be effective. Hospitalizations should be extremely limited because they reinforce helplessness and the inability to maintain self-control. I have repeatedly seen people move to a growth perspective only after several crises have been managed successfully and fear reduced.
- 2) Some people are so impressed by the power of mental illness that they have given up all hope of rehabilitation. They often attribute all of the member's feelings to the illness as though it has swallowed them whole, leaving none of the person and no free-will or responsibility remaining. This deprives the member of any actual feelings or actions and makes medication the answer to everything. The goals become maintenance, stability, quiet and safety. Often how depressed the member is, under all this, is overlooked and minimized. As with demoralized members, education to separate the member from the illness and psychosocial rehabilitation success are often helpful in restoring hope.
 - 3) Some people minimize the importance of the illness and often blame the member or themselves. The member is described as "lazy" or "bad" and the illness overly personalized, "why is he doing this to me?" Anger and resentment grow on all sides. I think this is often the case with "high expressed emotion". Once again, education to separate the person from the illness is helpful. Also, distancing and depersonalizing some of the relationships themselves can help.

These last two problems are two extremes of the same dilemma of how to cope with seriously handicapping mental conditions. As a member put it, "I have to be taken off medication entirely and leave the Village or be put in the state hospital." The best approach is somewhere in between. Neither can these illnesses be erased, nor should they take over lives. They are serious obstacles that need to be adapted to, treated (often with medications), coped with, and ultimately, lived with. If the Village takes on more of the burden of dealing with the illness, the family can return to being a family interacting with the healthier parts of the member.

We find as we work intimately with members, we often start feeling like parents. But it is not like being the parent of a small child. More often, it is like being the parent of adolescents. This makes sense, since it is often in adolescence that illness, trauma, or substance abuse interrupted their development. Looking back at the last two problems again, they are analogous to common parenting problems of adolescents: either over protecting and not teaching self-responsibility or getting angry at their acting out. It has helped us to remember how many mistakes, even dangerous ones, we made during our own adolescence. Our mental health system rarely supports those mistakes so needed for growth. Many of us further remembered that we really did not achieve adulthood until we moved out of our parent's households, and many of our members seem to need that step as well. Gratifyingly, we have seen many of our members move on to adulthood, taking care of their own households, working, getting married, having and more importantly, raising children, completing their educations, taking real vacations, and even restoring adult relationships with their families, no longer dominated by shame.

As their psychiatrist, I have found that my treating members as responsible adults, able to meaningfully collaborate with me, has been an important factor in their often painful process of growing into handicapped, but functioning, adults.

I have to admit that I was disappointed when I reread that article to include it in this book. In some ways it seems so limited. It was particularly disconcerting to read that I thought that seeing things from “incompetent” patients’ point of view was a temporary tactic until I could get power to force them to do it my way. Over the last couple weeks, I’ve figured out what was wrong: Although I was trying to be empowering and rehabilitative, I was still using an illness centered model instead of a person centered model. The entire discussion is about how to cope with illnesses, not how to cope with life. That’s why it feels so limited.

Recently I listened to a presentation for psychiatrists telling them that the primary difference between what they’re doing now and recovery is that they’ll have to negotiate more and give orders less. If they do that they’ll create medication collaboration, but not recovery, because they’ll still be illness centered instead of person centered. Medication collaboration is an important transformative skill that’s a prerequisite for recovery based psychiatry, but there’s a long way to go from here.