

Over the past three years I have been a consultant to LA County DMH as they try to implement California's Mental Health Services Act and become more recovery oriented. They are probably the largest public mental health system anywhere, directly running 21 CMHCs averaging over 200 adult clients each. I have been in almost all of those clinics and worked with the line staff and program directors. The motivation for change, especially recovery based change is highly variable. The work has been slow, frequently disrupted by serious budget cuts. I try to be a consistent advocate for recovery while understanding their day to day lives. Here is something I wrote about the controversial issue of getting off medications as part of that effort.

Can I Recover and Stop My Medications?

(2009)

Recently I received an e-mail from an administrator trying to promote recovery based transformation asking me to respond to one of the clinic psychiatrists. The psychiatrist's e-mail said, "The link to the Empowerment Center should be removed from this site [the DMH Wellness and Client Run Centers site] as it states clearly on their website that most people with schizophrenia will be able to discontinue their medications and "recover". Not the message DMH should be sending to anyone." It went on to insert the objectionable paragraph,

"Research carried out at the National Empowerment Center has shown that people can fully recover from even the most severe forms of mental illness. In-depth interviews of people diagnosed with schizophrenia have shown that these people are capable of regaining significant roles in society and of running their own lives. Though they have recovered from their mental illness they, as everyone, continue to heal emotionally. In most cases they no longer need medication and use holistic health and peer support to continue their healing. Our findings are consistent with long term studies carried out in this country by Dr. Courtenay Harding and colleagues, and in Europe by Dr. Manfred Bleuler and Dr. Luc Ciompi. These workers have shown that over a 20-30 year period a majority of people recover from even the most severe forms of mental illness. In addition, cross cultural and historical studies indicate that chronic mental illness is recent phenomenon of Westernized countries. Recent studies by the World Health Organization show that the rate of recovery from severe mental illness is much better in third world countries than in Western industrialized countries. Historical evidence points out that the rates of recovery were much higher during the 1830-40's in this country when there was a much more optimistic view of recovery. (See accompanying article on moral therapy.)" (her underlines)

The psychiatrist added, "I would not want any of my clients to think they can stop taking their medication."

The administrator said she didn't intend to remove the link to the National Empowerment Center and asked me for "a respectful, intelligent, and psychiatrically sound response." Since this issue comes up so often, I decided to write a lengthy answer.

Short response:

Bottom line 1: This psychiatrist is like the boy sticking his fingers in the dike holding back the flood. She sees hundreds and hundreds of people mostly for brief, indefinite medication refills some of whom she barely knows. There isn't an opportunity for thoughtful, individualized, targeted medication strategies or to guide someone in stopping their medications watching for warning signs of relapse together. At her CMHC there are virtually no effective therapeutic treatments offered for primary or "secondary" conditions, minimal rehabilitation or recovery services, not much help in the client's "natural supports," and not much ability to relieve their poverty besides SSI. Within the medication management dominated environment of the clinic, no wonder she focuses in on the recovery and medication portions of the National Empowerment Center's website. Without the availability of responsible ways to promote recovery and help people no longer need medications, no wonder she says, "I would not want any of my clients to think they can stop taking their medication."

Bottom line 2: The National Empowerment Center is not a rabidly anti-psychiatry or anti-medication organization despite some efforts to portray it that way. The studies they cite are real. Recovery does occur, even with schizophrenia. They have thoughtfully studied what helps people recover, including themselves, and come to the conclusion that indefinite medication stabilization isn't a golden bullet despite its pervasiveness. They have developed an array of useful tools including Dan Fisher's Personal Assistance in Community Existence (PACE) and Patricia Deegan's Intentional Care Standards. If we are to continue pursuing recovery based system transformation we should learn from them. It's bad enough we work in the CHMC trenches with such a limited view. We shouldn't intentionally blind ourselves further by refusing to look at what other responsible people, including the National Empowerment Center, are doing in other settings.

Long response:

1) When I was a psychiatry resident in the mid 80's I learned that Major Depression episodes went on about 6 – 12 months and if someone had been symptom free for that long we should try to taper off their medications to see if their episode was over. For mania the time was shorter, 3 – 6 months, but the risk of relapse was higher. Even for schizophrenia I was taught a variety of targeted medication strategies including drug holidays, trying to balance the risk of tardive dyskinesia from long term continuous high dose antipsychotics with the 70% risk of relapse over 2 years without antipsychotics.

Of course, back then the available medications were first generation antipsychotics, Lithium, and tricyclics. As newer medications have been developed with less side effects, and presumably less long term risk, the balance tipped increasingly towards indefinite medication maintenance.

I should also note, that all of the targeted strategies required substantial individualization, psychiatrist time, patient education, and collaboration, all of which are in short supply in today's CMHCs. By contrast indefinite medication maintenance requires only cursory, occasional psychiatrist contact and appointment compliance.

I was also taught a variety of effective non-medication treatments, including CBT for depression, relaxation training and systematic desensitization for anxiety conditions, brief trauma therapy for PTSD and acute traumas, brief psychodynamic psychotherapy for neurotic symptoms, and 12 step therapy for substance dependence. The thinking was that if one of these conditions was substantially contributing to the symptoms I was medicating that after effective treatment their medications might be able to be stopped.

I should note that all of those diagnoses got relegated to secondary diagnoses when we targeted only “Major Mental Illnesses” for service and that almost all of those treatments have also disappeared from our CMHCs. This has had the effect of dramatically increasing the number of people with chronic mood disorders and even schizoaffective disorders on indefinite medication maintenance in our clinics. It’s unclear how many of them would recover with effective treatment for these “secondary disorders.”

(I once went to a presentation by the director of Harvard’s Borderline Personality Disorder clinic, where he said that only 1 in 40 of his clients came with the diagnosis of Borderline – most were diagnosed as Bipolar II and given indefinite mood stabilizers and other meds – but when they gave them intensive DBT within 5 years 70% recovered and no longer met the criteria for Borderline or needed medications.)

By the way, this is not just the psychiatrist’s issue. I did a site visit at this CMHC recently and we asked the group of team leaders what services they would offer a moderately depressed returning client to try to help her recover. After “Get her back on her meds” they fell silent. They had nothing. The mental health professionals had been reduced to doing assessments, paper work, and a little “case management.” No one had any faith in anything besides medications to help people.

Whether she realizes it or not, this psychiatrist working in a standard CMHC doesn’t have the choice of including either individualized targeted medications or effective therapy in her treatment plans. That likely has an impact on whether her clients can successfully stop taking their medications. Our efforts to redesign services to include Strategic Services and Supports and retrain staff may have an impact on this deficit.

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2) What about schizophrenia? (Though before we go on, note that in our CMHCs we don’t advise anyone with any diagnosis to get off medications.) We all know that isolation is bad for people with schizophrenia. The more time they spend alone talking with their hallucinations, pacing, smoking cigarettes and drinking coffee, with nothing to look forward to or live for, the worse they will do. Does that mean that they’ll do better if they aren’t isolated?

The National Empowerment Center’s PACE program, and others like it, advocate for lots of emotional connections, self exploration, social involvement, active self management of illness, meaningful roles, and community involvement put together in an active recovery approach to mental illnesses including schizophrenia. We all cheered when we saw John Nash use this effectively in the movie “A Beautiful Mind” instead of medications even as his hallucinations persisted in the background. But the likelihood is, once again, that CMHC psychiatrists and clients will never be exposed to this approach to learn who

on their caseload it might help. We're building Wellness and Client Run Centers precisely to try to create those opportunities.

At this point a pervasive counterargument usually surfaces: Those approaches may work for some people but "we treat the sickest of the sick in our clinic." In fact, CMHCs do not treat the sickest of the sick. They're usually too impaired and uncooperative to even come to clinic appointments. Take a look in the ER, jail, psych hospital, homeless on the streets, or even in their family's back bedroom. That's where most of the sickest of the sick really are.

We do, however, treat "the poorest of the sick." All of our clients are strikingly poor. By definition, they're indigent. They're people for whom SSI would be a step up. Most of them didn't become poor because of downward social drift because of their illness. Most of them have been poor their entire life. That generally means they have had limited opportunities in life, limited education, limited skills and support, and limited experience with empowerment. Therefore, they don't have in their "natural supports" the elements needed to recover, so if we don't provide them no one will. Also, they're likely to think that an impoverished life, stabilized on SSI, is about as good as it would be likely to get even if they did recover.

We may be right, that our clinic clients are less likely to recover than Courtney Harding's Vermont and New Hampshire state hospital samples, but not because ours are sicker, maybe because they're poorer. By the way, Courtney notes that people hospitalized after SSI was invented recovered less commonly even in her sample.

If we can't impact their poverty substantially and don't create opportunities, skills and supports, education, and empowerment for them, maybe they should just stay on their medications. Even the Empowerment Center wouldn't be too hopeful.

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3) No matter what we tell them, of course a lot of our patients do stop their medications. A fair number don't even come back after the first intake appointment when they learn all we're offering is medications. Since they know we don't approve and we don't have a "try to get off your medications with support" track, they generally drop out of all services when they get off of medications.

Many people just disappear and no one knows why. Every month there's a new list of charts to close. Some of them come back, but who? Not the ones who do much worse without medications unless they have strong family support. Those clients end up with the sickest of the sick in the ERs, hospitals, jail, streets, or in their family's back room. Only a fraction of the dramatic deteriorations make it back to the clinic. The ones who do more or less the same or even better without their medications don't return either. Why would they come back? The ones who come back are the ones in the middle. They're the ones who get substantially, but not catastrophically worse without meds. They're the ones who realize medications help them and are basically together enough to come to the clinic for appointments to get them.

After a while our clinic case loads are filled almost exclusively with people who are helped substantially by medications and keep coming back to get them, but never get well enough to stop them. These people stick with us gratefully year after year, filling our hours, never moving on, and our caseloads go up and up.

If we're not careful, we might come to the conclusion that everyone with mental illness is helped substantially with medications but never get well enough to stop them because that's who we spend all our time with. Courtney Harding has a name for this effect – The Clinician's Illusion. We think the universe of schizophrenia is who we treat, when in fact we treat a very selected sample, who, by the way are not the same sample as the Empowerment Center interviewed to figure out how people recover.

If we offered services besides medications, if we didn't require people to be on medications before we helped them with housing or employment or benefits, if we supported people while they were trying to get off medications and learned to rely on emotional and interpersonal help, maybe we'd have more people in our clinics who could get off medications. But, we're not doing any of those things, so we continue to select for people who should stay on their medications.

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4) While the psychiatrist who wrote the e-mail has been working at the clinic, I've been across town working at the Village on an FSP team, in our Homeless Assistance Program, and at our Transitional Age Youth Academy. I work with people who on paper look the same as the clinic clients. They have the same diagnoses, disabilities, and poverty. Most of them have even been in a clinic, but they didn't meet the profile to stay there for years improved somewhat on meds. For a whole variety of reasons they ended up hospitalized or jailed, or homeless, or in their family's back room. We have extremely few drop outs so we keep a variety of people, some for many years. We have more resources than the clinic to offer a variety of services to help them heal and recover.

What we've found when we offer sanctuary and hope and belonging and empowerment and self responsibility and meaningful roles is that some people do recover. Some never take meds, some start only after years of refusing or stopping and starting, some stop meds after years of taking them. Frankly, whether they take medications or not, isn't our main concern if they're achieving their goals and building a life. I don't know what the percentages are because I do clinical work, not research, and besides I never know who the people being researched really are or what they're getting. But I do know that the National Empowerment Center's interviews are real and that Courtney Harding's studies are real and that some people with schizophrenia can recover with or without medication.

So my final response is even though the National Empowerment Center doesn't fit very well into the way our clinics work now, keep the link anyway and keep working as hard as you can to transform our system, to find a way to treat "secondary diagnoses," to individualize medications, to add strategic services, full service partnerships, and wellness centers, to create a variety of approaches to help a variety of people recover.